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Work in Progress: A Conceptual Framework for Understanding the Successful Vocational Experiences of People living with HIV in Canada

Oliver, Brent William

UNIVERSITY OF CALGARY

Work in Progress: A Conceptual Framework for Understanding the Successful Vocational

Experiences of People living with HIV in Canada

by

Brent William Oliver

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Abstract

Income support and labour force participation are critical issues for people living with HIV in Canada (PHAs). The objectives of this study were to identify factors that support or deter labour force participation, and to develop a conceptual framework to describe the processes and structures that shape PHAs' successful vocational experiences. Community-based research methods and a grounded theory framework were used to explore the perspectives of people living with HIV in Canada who have sustained successful participation in the labour force. Purposive and theoretical sampling was conducted in the provinces of Ontario, Alberta, and British Columbia. Semi-structured interviews were conducted with 31 people living with HIV who were successfully engaged in the labour force for three months or more. Sampling was conducted concurrently with data analysis until saturation was achieved within key emergent thematic categories. The data were transcribed and analyzed using grounded theory coding methods and NVIVO computer software. Study findings identified six intersecting thematic categories that summarized participants' experiences of working successfully. These have been conceptualized within a social ecological framework and include factors at the personal, work, community, and public policy level. These results contribute to an expanded contextual view of labour force participation for people living with HIV and highlight the importance of community and structural level factors including income support policy, access to medication, and vocational service provision. Results will be of interest to advocates, policy makers, and those working in community-based AIDS service organizations.

Dedication

I dedicate this work to my mother, Shirley Coutts. She supported me as a single parent while I pursued my first social work degree. Throughout those difficult years she made many sacrifices so that I could complete my education. She never gave up on me.

Acknowledgements

In many respects this dissertation has been a team effort and I wish to acknowledge all those who have contributed to the success of this research. This study was made possible by the 31 individuals who contributed their knowledge and experiences of successfully working while living with HIV. Thank you for your honesty, your reflections and your valuable time. I am inspired by the passion and determination you bring to your work.

I have been fortunate to study within the Faculty of Social Work at the University of Calgary where I benefited from the exceptional commitment and dedication of the entire faculty and staff. I extend my appreciation to my supervisor, Dr. Catherine Worthington. I have greatly valued the guidance you provided and the time you devoted to my learning process. Your mentorship, support, and rigour assisted me in my development as a community engaged researcher. You have been a valuable role model in how to conduct ethical, responsive, and relevant community-based research. I am also grateful to the faculty who served on my dissertation committee including my co-supervisor, Dr. David Este, Dr. Jackie Sieppert, and Dr. Jessica Ayala. Thank you for the time you have invested, and for your support, critical feedback and encouragement.

This research benefited from the contributions of many community partners and collaborators from across the country. My appreciation goes out to the community advisory committee and staff from the several AIDS service organizations who worked alongside me throughout the four years of this study. I sincerely hope that the results of this research will in some way benefit your work in the community.

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CHAPTER ONE: INTRODUCTION

1.1 Introduction

HIV/AIDS has emerged as an enduring and complex medical and social reality in Canada. At the end of 2011, the Public Health Agency of Canada estimates that there were nearly 71,300 people in Canada living with HIV and it is estimated that there are approximately 3000 new infections each year (Public Health Agency of Canada, 2009). Due to the success of combination therapy, HIV is frequently framed as an episodic disease, and people living with HIV increasingly report experiencing unpredictable cycles of wellness and illness (Bhaskaran et al., 2008; Hoy-Ellis & Fredrikson-Goldsen, 2007). Consequently, an increasing number of people living with HIV are experiencing significant improvements in their health status and are considering labour force entry, reentry, or are maintaining paid employment. Consequently, labour force participation has been identified as an important determinant of health and a serious social issue facing people living with HIV in North America (Braveman, Levin, Kielhofner, & Finlayson, 2006; Ferrier & Lavis, 2003; Rueda et al., 2012).

Social workers have been active in HIV care and social research in Canada from as early as 1983, contributing to community practice in a variety of settings, such as AIDS service organizations, community health centres, social housing agencies, and advocacy organizations (Canadian Association of Social Workers, 1997; Rowe & Ryan, 1999). This is complex work requiring a concurrent focus on intersecting factors at the personal, community, and structural levels. The core competencies and skills exemplified in social work are congruent with these demands, as are the professions' explicit focus on social justice, strengths perspectives, and ecological and anti-oppressive theoretical frameworks (Canadian Association of Social Workers, 2005; Mor Barak, 2000; Ungar, 2002).

This dissertation utilizes community-based research principles and grounded theory methodology to explore the perspectives of people living with HIV in Canada who have successfully maintained participation in the labour force despite the potential barriers and obstacles. The study offers insight into the perspectives of people living with HIV who are successfully engaged in the labour force, identifies factors that enable them to sustain ongoing employment, and develops a conceptual framework of the processes and structures that shape their success in employment.

This introductory chapter presents the contexts that have shaped this study and elaborates on the study objectives. The potential contributions of the study with respect to theoretical development and practice are also discussed. The chapter concludes by introducing the organizing structure of the dissertation.

1.2 Setting the Context

Labour force participation and income support issues have been identified by people living with HIV and community service providers as one of the most pressing issues facing those living with HIV in Canada (Worthington & Krentz, 2005). Studies conducted after the introduction of combination therapy suggest that approximately half (ranging from 42%-62%) of people living with HIV in industrialized countries are unemployed (Burgoyne & Saunders, 2000; Cunningham, Anderson, & Katz, 1999; Dray-Spira, Gueguen, & Lert, 2008; Ezzy, de Visser, & Bartos, 1999). This compares with broader statistics on employment and disability in Canada indicating that close to nine out of ten people without disabilities participated in the labour force. For those Canadians living with a disability that figure is six out of ten (Statistics Canada, 2008).

The unemployment rate is an important economic gauge for people with disabilities as it measures people who were actively searching for employment, and able to work, allowing for an

appropriate comparison with the non-disabled population. In Canada, unemployment rates for the years 2001-2006 (a period of unprecedented economic growth) for people with disabilities was 10.4% compared to 6.8% for the non-disabled population (Statistics Canada, 2008). These statistics establish Canada as an industrialized jurisdiction with one of the highest income disparities between people with a disabling condition such as HIV and those without (Stapleton & Procyk, 2011).

The connections between health and labour force participation are complex; however, it is clear that labour force participation is an important determinant of health for people living with HIV (Health Canada & Wellesley Central Hospital, 1998; Rueda et al., 2012). Labour force participation can provide a means to a sustainable income and access to a range of important social benefits, such as medical coverage and long-term disability supports (Brooks & Klosinski, 1999; Conyers, 2004b; Ferrier & Lavis, 2003; McReynolds, 2001). Furthermore, successful employment can also lead to enhanced psychological and emotional functioning and an increased quality of life among people living with HIV (Hergenrather, Rhodes, & Clark, 2005).

Unfortunately, barriers remain for people living with HIV who are interested in returning to or remaining in the paid workforce. Foremost among these are issues such as the episodic nature of the disease, workplace discrimination, lack of flexible income protection programs, and the lack of supportive policy structures (Ciasullo & Escovitz, 2005; Conyers & Boomer, 2005; Escovitz & Donegan, 2005; Ferrier & Lavis, 2003; Maticka-Tyndale, Adam, & Cohen, 2002; Worthington, O' Brien, Zack, McKee, & Oliver, 2009). In Canada, a variety of provincial and federal social policy measures have been put in place with the goals of reducing stigma and discrimination as well as the impact of economic insecurity arising from disability (Stapleton & Procyk, 2010)

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Two such examples are the Canadian Charter of Rights and Freedoms and the Canadian

Human Rights Act. These federal policies are designed to protect access to the labour market for

persons with disabilities by prohibiting discrimination based on physical or mental disability

(Galarneau & Radulescu, 2009). Despite this, 25.5% of unemployed persons surveyed as part of

Statistics Canada's 2006 participation and activity limitation survey reported that they had been

denied a job because of their disability status (Statistics Canada, 2008). Federal, provincial, and

private sector income support policies and programs provide a range of ways that those living

with HIV can access support. The programs commonly involving those living with HIV include

the Canada Pension Plan disability program (CPPD), Employment Insurance sickness benefits,

private disability insurance, and provincial social assistance benefits (Anderson & Brown, 2005;

Stapleton & Procyk, 2011). In 2008-2009, these programs provided a total of 17.9 billion in

financial benefits to people living with a disabling condition; 8.1 billion through provincial

disability social assistance benefits, 4.1 billion through CPPD and 4.7 billion through

employment-based long-term disability plans (Stapleton & Procyk, 2010).

A variety of systemic issues related to these income support programs have been well

documented as having a fundamental impact on people living with HIV. Canada's income

support programs have been criticized as having several different payers, no comprehensive

central administration, and gaps in eligibility (Stapleton & Procyk, 2010). These systems

frequently leave those who rely on them to navigate a system of conflicting and poorly integrated

policies and programs (Canadian HIV/AIDS Legal Network, 2005). Regrettably, most of these

programs are not designed for episodic conditions, frequently require recipients to refrain from

work, and fail to incorporate a standardized terminology regarding disability (Stapleton &

Procyk, 2011; The Canadian AIDS Society & The Canadian Working Group on HIV and Rehabilitation, 2003).

Vocational rehabilitation programs for people living with HIV are in the early stages of development and limited research evidence exists to assist service providers and policy makers in developing social policy and effective community programming that could support the vocational needs of people living with HIV (Ciasullo & Escovitz, 2005; Conyers, 2008). Survey data from Canadian health care providers suggest that there are a range of challenges attributed to accessing and delivering these services including a lack of availability, restrictive policies, stigma and discrimination, and a lack of knowledge of HIV among rehabilitation providers (Worthington, O'Brien, Meyers, Nixon, & Cockerill, 2009). Comprehensive data regarding the type of employment supports people living with HIV are currently accessing are not available, raising questions as to the nature of these services and the associated benefits. Additionally, evidence related to the experiences of people living with HIV who have received vocational services is a gap as is relevant and integrated theory that can inform the development of specific vocational support programs and policies (Braveman, Levin, et al., 2006; Conyers, 2008).

Complicating this terrain are the inherent complexities of labour force participation issues and the diversity of populations affected by HIV. For instance, within Canada, HIV has had a disproportionate effect on some of our most historically vulnerable communities, including gay, bisexual and other men who have sex with men, Aboriginal people, people who inject drugs, and people who have immigrated from countries where HIV is endemic; all populations that have traditionally had differing levels of engagement in the labour force and faced challenges related to employment (Public Health Agency of Canada, 2009). Thus, an additional priority in HIV and labour force participation research is to develop scholarship that is grounded in the perspectives

and experiences of people living with HIV in Canada and that can contribute relevant knowledge to community service providers (Conyers, 2008).

1.3 Locating the Study

The construction of knowledge, "is an outcome of social position, location, or situatedness producing a particular way the world is understood" (Genat, 2009, p. 109). Therefore it is imperative that qualitative researchers locate themselves in relation to their projects of inquiry. My interest in social issues for people living with HIV dates back to the early years of the pandemic and is informed by both my professional background in the field of social work and my personal commitment to the AIDS movement.

I first became involved in the AIDS movement while living and studying in Toronto, Ontario in 1990; a time in the epidemic when frequent deaths due to AIDS were common and were having a devastating effect on the gay community. As a gay man, my initial involvement in community AIDS activism was motivated by grief following the deaths of several friends and then sustained in the face of the widespread indifference and social stigma that characterized early responses to the AIDS epidemic in Canada. Progressively, I assumed a variety of roles within the AIDS movement, including as a social work student, activist, volunteer, service provider, consultant, and researcher. Regardless of role, I endeavoured to sustain a commitment to the goals and values of the community-based AIDS movement and with time was able to integrate this commitment with my professional work as a social worker; a project made easier by multiple synergies. Prior to my pursuit of doctoral studies, I worked within several community-based AIDS service organizations and was involved in planning and implementing HIV specific, front-line health and social services as well as contributing to public policy initiatives at the provincial and national levels. As the AIDS pandemic has broadened and

impacted other marginalized populations, the knowledge and expertise that I gained during my work in community organizations stimulated my interest in working with communities on the HIV research priorities that they have identified, and in informing social work practice and social change efforts.

My early work in the AIDS movement frequently involved contributing to community-based research initiatives. Community-based research embodies a recognition that the full and meaningful participation of people living with HIV is critical in articulating "non-oppressive and culturally relevant truths" (Howe, 1994, p. 525). The full and equitable participation of people living with HIV should be central to community-based research processes in the AIDS sector and served as a guiding principle for my dissertation research. I have endeavoured to adhere to this approach as I pursued a community engaged HIV research agenda. Accordingly, the need for this investigation was initially identified by community members and service providers and they have continued to be involved in all possible stages of the research. A community advisory committee whose membership included people living with HIV and community service providers has been instrumental in steering the research, generating an appropriate research question, supporting recruitment, and assisting with interpretation of the findings.

Within the constructivist tradition, the biography of the researcher is seen as influencing methodology and related research decisions (Bryant & Charmaz, 2007). Throughout this study, I endeavoured to reflect upon my own background and history as a gay man and an HIV service provider and their potential impact on the study. Having worked closely with many people living with HIV over the last decade, I entered the research field with a distinct perspective that influenced the process of inquiry. For instance, as an HIV negative gay man I have my own personal experience of the HIV epidemic and a sense of the many ways in which the disease has

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shaped my life. This lived experience has informed my response and shaped my work as a community ally, a social service provider, and a community-based researcher. Being sensitive and aware of the many realities that people living with HIV face, I approached this research with a desire to assist people living with HIV pursue their vocational goals. This shaped both the research question and the eventual interpretation of the results.

In several ways, I believe my personal location helped facilitate the research process. As a contributor to the AIDS movement for many years, I had ease of access for recruitment and my knowledge of the field informed the interview process. My sense is that these facilitated successful data collection and analysis. Additionally, my status as an openly gay man may have created an early rapport with some participants particularly other gay men who were interviewed for the research.

Nevertheless, there were also barriers that arose from my previous knowledge and experience of the disease. I was often caught off guard when interviews included participant narratives regarding intense emotional experiences related to seroconversion. These accounts often triggered my early fears regarding the disease and required bracketing. Having worked in the field for over 15 years, I at times assumed that I would be perceived as an ally or an insider. However early on I became aware that issues related to regionalism and intersectionality often meant I did not have an insider status and that many participants may have perceived me as an academic and a researcher as opposed to a community ally. This was particularly the case when interviewing individuals from backgrounds that differed from mine.

This inquiry builds upon two earlier community-based research studies in which I was involved as a collaborator and team member. The studies involved conceptualizing labour force participation for people living with HIV in Canada, and working with community stakeholders to

integrate the research findings into community products for education, policy, and program planning. The first, a Canadian Institutes of Health Research (CIHR) funded scoping review was conducted under the supervision of my doctoral supervisor, Catherine Worthington, and in collaboration with The Canadian Working Group on HIV and Rehabilitation (CWGHR), a national, non-governmental organization working to address the rehabilitation needs of people living with HIV. A major goal of this study was to use the research literature to develop a conceptual framework that could guide HIV specific vocational programs, policies, and services (Worthington, O' Brien, et al., 2009). As the research coordinator on the scoping study, I worked with a community advisory committee and the research team to review and summarize the literature on labour force participation for people living with HIV and synthesize the evidence into a conceptual framework. The resulting "HIV and Employment Framework" was summarized in a booklet and a series of fact sheets to highlight labour force participation issues for people living with HIV in Canada. Additionally, the scoping review identified a number of gaps in the research literature that provided the impetus for the current study; most notably a lack of studies addressing vocational programs and their potential impact on vocational processes for people living with HIV, as well as issues within the employment and public policy domains.

The second research project involved promoting and assessing the knowledge uptake related to the HIV and Employment Framework. The purpose of this CIHR-funded knowledge to action study was to promote and evaluate knowledge uptake of the HIV and Employment Framework among human resources professionals, vocational rehabilitation workers, and AIDS service organization staff. A webinar presentation, problem based learning modules, and a Frequently Asked Questions (FAQ) document were produced to accompany the framework booklet and fact sheets. The research findings indicated that webinar and focus group

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participants gained new knowledge and shifted organizational practices based on engagement

with the framework tools (Worthington, O'Brien, Zack, Popiel, Oliver, McKee, et al., 2010). I

served as a research member on this study, and was particularly involved in planning and

delivering webinars and supporting the development of the learning modules.

In 2009, as part of the original scoping study, we held a research consultation with

several community stakeholders including people living with HIV, representatives from the

AIDS Committee of Toronto, AIDS Calgary Awareness Association (now known as HIV

Community Link), and CWGHR. This consultation identified the need to better understand the

experiences of people living with HIV who have successfully returned to or remained in the

workforce after an HIV diagnosis and the factors that facilitate their continued labour force

participation. Research that offers a detailed understanding of these experiences is limited, and it

was recognized that this knowledge would benefit service providers and community members in

developing effective vocational services. Specifically, participants identified a need for relevant

information that could guide the development of essential pilot projects and that could inform

service provision across community sites in Canada. Additionally, research of this nature would

contribute new knowledge to the literature on labour force participation through a focus on

employment facilitators and the structural factors that shape the employment experiences of

people living with HIV. Thus, this dissertation research builds upon these earlier studies in

addressing identified gaps in the knowledge base and responding to the needs of community

partners and service providers.

1.4 Research Goal and Objectives

Given these identified gaps in the knowledge and the noted community needs, the

purpose of this study is to develop a conceptual framework identifying the important processes

and structures that shape the successful labour force participation of people living with HIV in Canada. Accordingly, this research draws upon grounded theory and community-based research methodologies to explore the following questions: *1) What are the perceived benefits, risks, challenges, and facilitators of labour force participation from the perspective of people living with HIV who have successfully returned to the workforce and remained employed?; and 2) What are the perceived benefits and challenges of community vocational rehabilitation services in assisting people living with HIV to return to the workplace and maintain employment from the perspective of people living with HIV?*

1.5 Significance of the Study

This study contributes to a broader research agenda identified by CWGHR through consultation with people living with HIV and other community stakeholders. A recent Canadian scoping study included a comprehensive literature review and stakeholder consultation in the development of key research priorities in the area of HIV and rehabilitation. Labour force participation and income support in Canada emerged as one of six key research priorities as did multi-methods research using an environmental contextual lens (O' Brien, Wilkins, Zack, & Solomon, 2009). As indicated, the research question for this dissertation emerged primarily from community concerns identified as part of a previous study. Consequently, this study both draws from and is informed by previous research, community priorities, and issues identified by people living with HIV and should prove relevant to those working to assist people living with HIV to address vocational goals and influence income support policy.

While labour force participation continues to be addressed through community engaged research in a variety of jurisdictions, relevant Canadian research knowledge remains limited. For example, the comprehensive literature review we conducted while developing the HIV and

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Employment Framework identified 285 relevant articles published prior to February 2009, from both the peer reviewed and grey literature; of these less than 10% addressed the Canadian context (Worthington, O'Brien, Zack, McKee, & Oliver, 2012). Notwithstanding a large body of research focussed on developing world economies, most of our understanding related to HIV and labour force participation originates from research conducted within the United States. This research has been valuable in informing community vocational initiatives particularly by providing insight into intrapersonal processes where similarities may exist across jurisdictions. Unfortunately, this U.S. based research is less pertinent in other jurisdictions at the community, public policy, and structural levels. Here, some significant differences exist between the Canadian and American context, notably among income support policies, medical and health care provision, and access to health care and medical benefits. This dissertation focuses on the perspectives of people living with HIV in Canada, specifically individuals living in Ontario, Alberta, and British Columbia. The study provides a comparative examination of some important factors related to labour force participation for people living with HIV, including some critical considerations at the public policy level. These data will assist CWGHR and their community partners to better understand the employment experiences of people living with HIV in Canada and will be a significant contribution to an emerging theoretical understanding of employment and HIV in Canada.

Of the relevant research on labour force participation for people living with HIV that we found within the scoping review, only 20% utilized qualitative methods and 6% involved participatory or mixed methods approaches (Worthington, O'Brien, et al., 2012). Several quantitative studies have begun to demonstrate the impact of employment on the health related quality of life of people living with HIV (Aranda-Naranjo, 2004; Blalock, McDaniel, & Farber,

2002; Cowdery & Pesa, 2002; Hays et al., 2000). There is a corresponding need for qualitative

and mixed methods research that can provide an in depth and nuanced understanding of the

diverse processes related to employment for people living with HIV. In Canada, the Employment

Change and Health Outcomes (ECHO) Study is investigating how employment affects health

outcomes of people living with HIV in Ontario. Results of this study will form a valuable

addition to the Canadian research. This dissertation complements the predictive capacity of this

effort by focusing on an expanded and complex understanding of the phenomenon. A qualitative

approach will assist in providing further, detailed description regarding the impact of

employment on people living with HIV and will contribute narratives that can better illustrate the

diverse perspectives of people living with HIV.

Due to the emergent nature of the issue and the relatively recent impact of HAART,

much of the previous labour force participation research has focussed on conceptualizing return

to work for people living with HIV (Braveman, Kielhofner, Albrecht, & Helfrich, 2006; Brooks

& Klosinski, 1999; Ferrier & Lavis, 2003; Goldblum & Kohlenberg, 2005; Hergenrather,

Rhodes, & Clark, 2004; Martin, Arns, Batterham, Afifi, & Steckart, 2006). As might be

expected, many vocational programs and initiatives have focussed on assisting people living with

HIV to weigh the benefits and risks of employment, assess their readiness, and return to work

should they so choose. There has been scarce attention, both in research and practice, on the

factors that support success in employment situations for people living with HIV and measures

that may assist them to manage HIV and sustain their employment. For example, in the HIV and

Employment framework we identified 17 broad strategies related to pre-work preparation and

supporting return to work yet were only able to classify three related to sustaining successful

employment (Worthington et al, 2012). This reflects an important gap in the research literature

and an area for attention in vocational programming, where a focus on placing clients in a job, often at the expense of assisting them to sustain employment, is a common occurrence (Hackett, Lent, & Greenhaus, 1991).

The strengths perspective is a social work practice framework that views individuals, groups, and communities, "in light of their capacities, talents, competencies, and hopes; and accounts for their abilities, knowledges, and resources" (Saleeby, 1996, p. 297). This dissertation is distinct in its focus on people living with HIV who have successfully participated in the labour force. As such, this research comprises a strengths based approach to labour force participation for people living with HIV rather than only conceptualizing the problems related to HIV and employment. It also includes a focus on the factors that support individuals in achieving their vocational goals and identifies the strengths and environmental resources available to assist them (Reamer, 1993).

In summary, this dissertation contributes significantly to the labour force participation literature in Canada. The study meets a demonstrated need for local, contextual knowledge in order to inform community responses; it provides insight into Canadian environmental factors influencing employment experiences of people living with HIV; and takes a strengths-based approach to an understudied and pressing social phenomenon.

1.6 Relevance to Social Work

This research holds relevance for social work at the practice, research, and theory level. Social workers are playing an increasingly critical role in the development of relevant public policy and the delivery of social services to people living with HIV. Whether employed within AIDS service organizations, through the mainstream social services framework or as policy analysts, social work practitioners have a continued and meaningful effect on the lives of people

living with HIV and their communities. The profession brings several potential and unique strengths to this field, including an awareness of the importance of anti-oppressive practice, structural analysis, community development, and a commitment to theorizing from practice (Fook, 2002; Mullaly, 1997).

In the increasingly professionalized field of AIDS work, social workers are often the only accessible and affordable support available to people living with HIV within community organizations. In the absence of HIV specific, vocational supports for people living with HIV, social workers are frequently providing employment counselling as part of their general caseload responsibilities. Existing evidence suggests that social workers and AIDS service organizations are those most involved in the provision of HIV specific employment supports. For instance in Ontario, 39.5% of AIDS service organizations reported providing employment counselling as part of general case management services (AIDS Bureau, 2009). Similarly, Canadian data indicate that health care professionals are more likely to refer their HIV positive clients to social workers and ASO's than to rehabilitation specialists for services related to vocational rehabilitation and income support (Worthington, O'Brien, et al., 2009). This is likely due to several issues and barriers related to accessing mainstream rehabilitation services for people living with HIV.

Social workers are well positioned to address critical factors at the interpersonal and environmental levels, thus complementing and expanding upon vocational services offered from a counselling psychology perspective. Critical forms of social work practice have traditionally proved compatible with the goals of the community-based AIDS movement. In particular, anti-oppressive practice (AOP) stands out as a relevant approach to guide social work practice with communities affected by HIV. AOP is a form of social work practice that analyzes and addresses

the social, cultural, and political conditions and challenges faced by individuals and groups (Baines, 2007). Based on the structural barriers faced by people living with HIV and the distinct gaps inherent within counselling psychology interventions, a social work practice framework premised upon the principles of AOP demonstrates the contribution that social work could offer to this area of practice. Working from a perspective that is informed by AOP principles provides a broad approach that begins to match the complex issues of stigma, discrimination, and marginalization faced by many people living with HIV in employment situations (Burke & Harrison, 2002).

Given that social workers are often on the front lines of service delivery in AIDS service organizations and are frequently providing employment counselling, it is critical that their perspective be represented in the development of vocational research, programs, and policies for people living with HIV. Findings from the study will support social workers to provide case management services to people living with HIV, and in developing effective programs to meet their vocational goals and in developing supportive public policies.

1.7 Thesis Overview

This chapter has provided an introduction to the study by contextualizing the issue, locating the study, providing a rationale for its relevance and significance, and summarizing the study purpose. Chapter Two provides an in-depth review of the previous research literature in the area of labour force participation for people living with HIV. Chapter Three describes the research methodology and methods used in this study. In sum, these chapters contextualize the current study, provide an understanding of the study objectives and identify the process used to answer the research questions.

Chapters Four, Five, Six, Seven, and Eight present findings from the study with each chapter focusing on a key area of the conceptual framework that emerged from the data. Specifically, Chapter Four provides an introduction to the research participants and an overview of the conceptual framework. Chapter Five presents a detailed discussion of the intrapersonal processes involved in working successfully. Chapter Six focuses on the interpersonal processes participants engaged in as part of ensuring successful vocational trajectories. Chapter Seven presents the findings related to institutional and community factors. Finally, Chapter Eight discusses the public policy level factors shaping participants' employment experiences. Chapter Nine concludes the dissertation by discussing the results in context and exploring the implications of the research.

CHAPTER TWO: LITERATURE REVIEW

2.1 Introduction

Labour force participation is a fundamental and significant form of human activity and one that has been conceptualized using a variety of perspectives and disciplines. This chapter reviews the literature relevant to HIV and employment in order to provide a foundation for the present grounded theory study. This review serves as a starting point for the dissertation, and provides sensitizing concepts; additional literature is introduced after the discussion of the conceptual framework where the results warrant.

Szmanski (1996) argues that, in general, career development theory is situated between a number of disciplines and informed by a, "theoretical mosaic" (p.49). This is also the case for the HIV and employment literature, which includes contributions from a variety of fields, including counselling psychology, vocational rehabilitation, social work, and the health sciences. Generally, the focus of this literature is shifting from a discussion of personal, and psychological constructs to a broader lens that examines the impact of socio-structural factors on HIV and employment (Auerbach, Parkhurst, Caceres, & Keller, 2009). Thus, in an area where no single vocational theory can be applied to all populations, the field benefits from an interdisciplinary approach, and a variety of conceptual lenses.

This chapter is divided into fourteen sections. The section immediately following this one discusses the role of extant literature in grounded theory methodology. Section three explores the role of work in people's lives and introduces some broad concepts related to labour force participation and vocational rehabilitation. Section four introduces and discusses the concept of episodic disability. Section five introduces the main themes identified in the HIV employment literature and sections six through thirteen reviews each of these major themes. Finally, section

fourteen briefly summarizes the literature review and discusses some of the limitations of the current knowledge base.

2.2 Addressing the Extant Literature in Grounded Theory

This study draws upon grounded theory, an approach to research that aids researchers in generating theory from qualitative data. Within grounded theory there is a high degree of ambiguity regarding when a researcher should conduct a review of the existing literature. Accordingly, this section summarizes the current views on literature review within grounded theory and establishes a rationale for the current approach.

Appropriate approaches to the pre-existing literature have been a topic of debate among grounded theorists who generally value the ability to approach data with an open mind (Dey, 1999). In *The Discovery of Grounded Theory*, Glaser and Strauss (1967) encouraged researchers to remain theoretically sensitive to their research topics; i.e., to develop and make use of existing theoretical insight into one's area of research while simultaneously considering the emerging data. They subsequently went on to advise researchers to ignore the related literature, at least until some categories and concepts have been established. In later publications, they offered additionally ambiguous positions on the status of the extant literature leading to a degree of confusion within the discipline. For example, Strauss and Corbin (1998) stressed the importance of using accumulated knowledge during grounded theory data analysis, and Glaser (1978) has since argued against "naïve inductivism" suggesting that researchers incorporate theoretical sensitivity and use established coding families (p.57).

Subsequently, some contemporary grounded theory authors posit that the researcher should enter the field with no formal review of the literature, while others note the importance of understanding the discourse surrounding their topic (Bryant & Charmaz, 2007). In summarizing

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and clarifying these debates, Charmaz (2006) argues that the literature review provides an opportunity for the researcher to summarize and evaluate the literature as well as situate themselves in relation to the current discourse. She highlights the importance of sensitizing concepts, "ways of seeing, organizing, and understanding experience that are embedded in our disciplinary lenses" (Charmaz, 2000, p. 515). Used as "points of departure from which to study the data", constructivist studies can incorporate sensitizing concepts into the inquiry without forcing preconceived notions on emergent theory (Charmaz, 2006, p. 259) . My positionality in relation to this study is consistent with such an approach. Having worked in the community-based AIDS movement for a considerable period of time, and having explored this issue as part of an earlier study, my knowledge provides me with a specific point of departure and a variety of experiences that inform my perspective on HIV and employment. These experiences have been shaped and constructed in relation with others, including researchers, community service providers, research participants, and people living with HIV. Hence, past knowledge and experience influence this inquiry rather than determine its findings (Charmaz, 2000). Consequently, the following review of the HIV and employment literature serves to describe sensitizing concepts, and provides a suitable grounding for this dissertation (Charmaz, 2000; Dey, 1999).

2.3 Work in People's Lives

Work is one of the most complex, dynamic, and pervasive forms of human activity. It is the medium through which individuals acquire basic life requirements and a mechanism by which individuals create quality of life for themselves and their families (Korman, Mahler, & Omran, 1983). In general, work assists us in defining who we are and what we hope to accomplish in life (Warnath, 1975). The issue of labour force participation for people living with

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HIV is embedded within a broader discourse on work, employment, and vocational development, which provides little in the way of a single, unitary framework from which to form an understanding of the phenomenon.

In an attempt to better understand the general factors that shape and influence individuals' work trajectories, vocational psychologists have contributed several dominant concepts to the field. Generally speaking, most of these are connected to the central organizing themes of career choice, vocational development, and career decision making. Defined as an "evolving sequence of a person's work experience over time" (Osipaw & Fitzgerald, 1996, p. p.50), the foundational concept of "career" has formed the basis of this developmental discipline which has traditionally focused on providing vocational guidance to individuals. Within this perspective, "vocational development" is seen as a key term and is commonly characterized as the "skills, knowledge, interests, choices, and behaviors that are acquired before, during and after entry into the workplace" (D. Blustein, McWhirter, & Perry, 2005, p. 141). The concept of "vocational behavior" is also foundational in vocational psychology and involves choosing, entering, and adjusting to one's occupational role (Osipow & Fitzgerald, 1996). The basic supposition of this perspective is "that each individual with adequate motivation, information, and guidance can, over the life span, move through the vocational process to satisfying job goals that allow him or her to express personality characteristics or implement self-concept" (Warnath, 1975, p. 422).

Thus, much of the vocational research, theory, and practice literature from this perspective assumes labour market equity and stresses personal agency over environmental barriers. These assumptions prove problematic when conceptualizing work for those from marginal social locations who traditionally encounter distinct vocational barriers (Warnath,

1975). In response to this shortcoming, several authors have attempted to re-conceptualize work from a more critical lens. Blustein (2005), Borgen (2005) and Richardson (1993) all recognize that vocational trajectories are structured within an inequitable distribution of wealth, power, and resources. Additionally, they suggest that the opportunity for success in employment is limited to those from select groups who commonly have increased access to resources and more freedom to make career choices (Blustein et al., 2005; Borgen, 2005; Richardson, 1993). They note that many individuals cannot seek vocational fulfillment because of disability, disease, sexism, racism and other forms of discrimination (Borgen, 2005). Furthermore, racial minorities, the poor, and people with disabilities are almost totally excluded from traditional vocational psychology research (Richardson, 1993). Consequentially, the environmental and social factors that impose restrictions on persons with a health condition such as HIV are rarely acknowledged or addressed in theory or practice (Elliott & Johnson, 2008).

An alternative means to conceptualizing work is offered by Richardson (1993) and echoed by Blustein (2005), Borgen (2005), and Elliott and Johnson (2008) who advocate shifting from a focus on career development to the study of "work in people's lives". Rather than focus on the concept of career, they argue for the need to consider people and their work in a broader context and from diverse social locations such as race, class, gender, ability, and sexual orientation (Richardson, 1993). Situated within a social constructivist paradigm and in place of a universal vocational theory, this approach allows for separate theories for individuals from diverse locations and involves "a multitude of stories about work in people's lives" (Richardson, 1993, p. 429). Within this approach, they argue, work would be redefined as not just a means to individual success or a way to earn a living, but also recognized as an essential activity that

brings individuals into relation with others (Blustein et al., 2005; Borgen, 2005; Richardson, 1993).

Accordingly, much of the HIV and employment literature responds to an identified need to develop specific, contextualized knowledge regarding labour force participation and the diverse populations affected by the disease. As this is the case, a great deal of the HIV and employment literature can be characterized as contributing to the project of studying work in people's lives, providing a diversity of understandings about the impact of employment on people living with HIV, and subsequently informing a broadened revision of vocational theory. Accordingly, the terms "labour force participation", "employment", and "work" are differing key terms that represent a variety of perspectives and summarize the diverse meanings that people living with HIV attach to notions of work. As such, they will be used interchangeably throughout the dissertation, with the intent of fully capturing the broad and diverse meanings attributed to this fundamental human activity.

2.4 HIV as an Episodic Disability

HIV is considered a permanent illness that often results in "recurring and unpredictable periods of good health and poor health" (The Canadian AIDS Society & The Canadian Working Group on HIV and Rehabilitation, 2003, p. 1). For this reason, HIV has been classified by some professionals and service providers as an episodic disability. An episodic disability may be experienced "in phases or episodes, with movement in and out of states of disability of varying severity over time" (Galarneau & Radulescu, 2009, p. 5). These periods of illness often pose serious long term consequences to an individual's health, income stability, and quality of life (Vick, 2012). Other forms of episodic disability include multiple sclerosis, chronic fatigue syndrome, fibromyalgia, colitis, Crohn's disease, lupus, epilepsy, asthma, osteoarthritis, diabetes,

cystic fibrosis, heart disease, and mental illness (Lightman & Vick, 2010). The 2006

Participation and Activity Limitation Survey (PALS) conducted by Statistics Canada suggests

that episodic forms of disability may be the most commonly experienced, noting that from 1994

to 2006 only 13% of people who reported a disability were affected by it during all 6 years

(Statistics Canada, 2008).

Historically, the term disability has been conceptualized within a medical model

perspective that tends to pathologize people experiencing disabling conditions and disregards the

wider cultural and social factors that created barriers for them (Beresford, 2000). In response to

challenges from critical social scientists and disabled people's movements, current

conceptualizations of disability have shifted towards a social model of disability where people

are viewed as being disabled by society rather than by their bodies, and disability policy is

shifting towards community inclusion and more interactive approaches (Beresford, 2000; World

Health Organization, 2011). While disability remains an evolving and contested concept it is

currently understood by the World Health Organization (2011) and their International

Classification of Functioning, Disability and Health diagnostic model as an umbrella term

referring to "the impairments, activity limitations, and participation restrictions that arise from

the interaction between an individual with a health condition and that individual's contextual

factors" (p.4). This distinction draws from bio-psycho-social understandings of functioning and

disability that assume a dynamic interaction between health conditions and contextual factors

(World Health Organization, 2011). This conceptualization is not inconsistent with the simplified

and easier to measure definition used by Statistics Canada in the PALS study where disabled

individuals are classified as "people whose daily activities are limited because of a health

condition or health problem" (Stapleton & Procyk, 2010, p. 2).

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Despite the tensions surrounding current notions of disability, some HIV advocates and service providers have adopted the term episodic disability, noting that there is currently no standardized terminology that successfully reflects the complexity of HIV (The Canadian AIDS Society & The Canadian Working Group on HIV and Rehabilitation, 2003). Several factors are cited as supporting this designation, notably that the progression of the disease is unpredictable and highly variable and that many people living with HIV experience temporary periods of ill health that often entail cycling in and out of the workplace (The Canadian AIDS Society & The Canadian Working Group on HIV and Rehabilitation, 2003).

These widely accepted notions regarding episodic illness and disability are consistent with the perspective of this research for several reasons. First, this dissertation involves community-based research principles and embodies a respect for the knowledge and perspective of people living with HIV and community service providers who have advocated for a social model of disability. Secondly, critical definitions of disability are consistent with social work values, the strengths perspective, and anti-oppressive practice; sensitizing frameworks guiding this investigation. Finally, these frameworks closely fit the lived experience of many people living with HIV as articulated in earlier studies from a variety of perspectives (Paul-Ward, Braveman, Kielhofner, & Levin, 2005; Proctor, 2002; The Interagency Coalition on AIDS and Development, 2005; Weir, Crook, Zack, Reeve, & O'Brien, 2003). Thus, these concepts will be used throughout this dissertation when describing and referring to HIV and its impact on participants' vocational success.

2.5 Major Themes related to HIV and Employment

The relevant literature on HIV and employment can be summarized into several broad themes that reflect research conducted in the area to date; 1) the motivation to work, 2) health

factors influencing labour force participation, 3) workplace environments, 4) public policy and income supports, 5) social structural factors, 6) vocational services for people living with HIV, 7) impact and outcomes of employment for people living with HIV, 8) theoretical understandings guiding labour force interventions for people living with HIV. Each of these topics has implications for the current dissertation research and will be discussed in the following sections of this review.

2.5.1 The Motivation to Work

In two publications (2006, 2008, Bluestein highlighted three core functions that work has the potential to fulfill for individuals living with HIV. These include the notion of work as providing a means to survival and power, a means of social connection, and as a means to self-determination (Blustein, 2006). Numerous studies in the HIV and employment literature document these functions, further demonstrating the conditions, beliefs, and motivators that structure labour force participation for people living with HIV.

With respect to survival needs, several studies have demonstrated that employment can provide increased access to critical financial resources, medical benefits, and health care. For instance, in focus group research with people living with HIV who were involved in vocational service programs, Conyers (2004a) found that individuals believed that work would provide them with increased financial resources and an increased sense of independence. Additionally, Brooks and Klosinski (1999) established that a desire for financial security and stability as well as sustainable medical benefits were primary reasons for people living with HIV wanting to return to work. Finally, in a recent observation, Conyers (2008) suggests that improved health has meant that many people living with HIV no longer qualify for disability income support benefits and are left little choice but to work in order to support themselves financially.

Several authors have explored the core beliefs and values with which many people living with HIV approach labour force participation. It appears that many individuals aspire to obtain employment that is rewarding, mentally stimulating, and that provides possibilities for career advancement (Brooks & Klosinski, 1999; Caulfield, Carey, & Mason, 1994; Dickson-Gomez, Knowlton, & Latkin, 2004; Jalbert, 1997; Maguire, McNally, Britton, Werth, & Borges, 2008). The perceived psychological and emotional benefits of work were cited in Brooks and Klosinski's (1999) study as primary motivations for returning to work. They found that people living with HIV were approaching employment with the expectation that it provide them with a renewed sense of purpose, increased feelings of self-esteem, and a sense of being productive. They also established that a desire to connect socially with other people as well as contribute to the community were additional motivators (Brooks & Klosinski, 1999). Other qualitative studies have reported that people living with HIV who are contemplating work believe that employment will increase their level of self-esteem and self-efficacy, better enabling them to address their quality of life and HIV prognosis (Hergenrather, Rhodes, & Clark, 2005).

Additionally, the HIV and employment literature suggests that the concept of work intersects with personal notions of identity. Braveman and Helfrich (2001) propose that occupational identity; a sense of who one is and wishes to become as an occupational being, is important in understanding the decision to work. Thus for some people living with HIV, vocational transitions might include the need to create or recreate a sense of identity in a new vocational role (Braveman & Helfrich, 2001; Dickson-Gomez et al., 2004; Goldstein, Kielhofner, & Paul-Ward, 2004). Some studies theorize that this sense of identity may be influenced by prevalent cultural values regarding work, documenting that people living with HIV experience pressure from family and peers to encourage them to contribute to society through

paid employment (Braveman, Kielhofner, et al., 2006; Hergenrather, Rhodes, & Clark, 2005; Nixon & Renwick, 2003).

2.5.2 Health Factors Influencing Labour Force Participation

As indicated earlier, many vocational and health disciplines recognize HIV as an episodic condition involving unpredictable periods of disabling illness. The related uncertainty regarding disease progression creates instability and insecurity for many people living with HIV (Escovitz & Donegan, 2005; Hergenrather et al., 2004; Rosolen, 2002; Vetter & Donnelly, 2006), and the employment experiences of these individuals are frequently characterized by multiple transitions in and out of the workplace due to numerous cycles of wellness and illness (O'Brien, Bayoumi, Strike, Young, & Davis, 2008). In some cases, this may lead to long periods of unemployment (Dray-Spira & Lert, 2007; Escovitz & Donegan, 2005; Paul-Ward, Kielhofner, Braveman, & Levin, 2005), creating a lack of professional experience (Dray-Spira & Lert, 2007) and low levels of job skills among some people living with HIV (Johnson, Reynolds, & Fisher, 2001; Oliva, Roa, & del Llano, 2003); factors which can inhibit success in sustaining stable employment patterns.

Health related issues are commonly cited as having a critical impact on the vocational success of those living with HIV. Length of time since diagnosis can play a pivotal role in successful employment, as those who are newly diagnosed may be less likely to have experienced major episodes of illness causing work stoppage. Indeed, the HIV and employment research has demonstrated that health status may be independently associated with employment status among people living with HIV (Dray-Spira & Lert, 2007). For example, in cross sectional studies, both Dray Spira et al. (2003) and Brooks et al. (2004) have found that employment status was associated with HIV prognosis and health status, suggesting that those individuals most

likely to successfully maintain employment are also more likely to be in better health. Additionally, several studies have established that receiving an AIDS diagnosis or living with an advanced stage of HIV disease can constitute a critical barrier to employment (Dray-Spira et al., 2003; Ezzy, de Visser, Grubb, & McConachy, 1998; Hergenrather et al., 2004; Rosolen, 2002; Van Gorp et al., 2007; Vetter & Donnelly, 2006). Accordingly, early access to combination therapy for people living with HIV can inhibit disease progression and contribute to longer term employment (Goldman & Bao, 2004).

Increased HIV symptomology and related health conditions are common challenges that frequently affect people living with HIV in the workplace. Anandan and colleagues (2006) used cross sectional analysis to identify the physical impairments most commonly reported by people living with HIV. These included fatigue, difficulty concentrating, and muscle aches, in addition to a variety of mental health issues such as depression and anxiety. Additionally, cognitive and neuropsychological impairments have been documented as negatively impacting people living with HIV in the workplace (Hyduk & Kustowski, 2003; McReynolds, 1998; Razzano, Hamilton, & Perloff, 2006; Van Gorp et al., 2007). Factors related to medication and combination therapy can also create health issues and serve as vocational barriers. Complicated and demanding medication scheduling regimens have in the past caused undue stress and impeded employment for some people living with HIV (Hyduk & Kustowski, 2003). Debilitating side effects attributed to some HIV medications including nausea, diarrhea, and fatigue can prevent people living with HIV from effectively contributing to the workforce (Bogart et al., 2000; Glenn, Ford, Moore, & Hollar, 2003; Werth, Borges, McNally, Maguire, & Britton, 2008b). In addition, other concurrent health issues, such as Hepatitis C co-infection and addiction may further compromise the health

status of some individuals and exist as subsequent barriers to employment (Dray-Spira, Gueguen, Ravaud, & Lert, 2007; Dray-Spira et al., 2003; Grierson et al., 2004).

Emotional and psychological issues are commonly cited as employment barriers for many people living with HIV and often precipitate their leaving the workplace. Depression is commonly experienced by many people living with HIV and consistently identified in the HIV and employment literature where it is characterized as an impairment to work and a contributor to decreased quality of life amongst people living with HIV. It is also however, recognized as a primary motivator for labour force participation. Additionally, people living with HIV have described their feelings of fear, anxiety, shame, and low self-worth as preventing their success in vocational settings (Brooks & Klosinski, 1999; Caulfield et al., 1994; Ezzy et al., 1999). Other mental health issues preventing labour force participation for people living with HIV include post-traumatic stress disorder, suicidal ideation, and other serious psychiatric disabilities (Blustein et al., 2008; Escovitz & Donegan, 2005; Johnson et al., 2001).

2.5.3 Workplace Environments

People living with HIV and vocational service providers have identified a need for low stress vocational opportunities that provide adequate support through workplace policies and reasonable accommodations (Allen & Carlson, 2003; Bell-Rowbotham, 1997; Conyers & Boomer, 2005; Gadd & Goss, 1997; Hyduk & Kustowski, 2003; Walch, Lezama, & Giddie, 2005). Unfortunately, these needs are in contradiction with the reality of many employment situations, as non-supportive work environments are frequently cited by many people living with HIV who are involved in the labour force (Caulfield et al., 1994; Hergenrather et al., 2004; Hyduk & Kustowski, 2003).

Using a qualitative, phenomenological design, Hunt et al. (2003) documented the career concerns of people living with HIV/AIDS. Results indicated a variety of issues related to negative workplace environments, including a lack of appropriate workplace accommodations and benefits, fear of discrimination, and poor knowledge of HIV among co-workers and managers. These concerns may be well founded as several studies have documented work environments that are hostile towards people living with HIV. A survey of 111 Quebec companies (2009) revealed that a large proportion of employers (60%) continue to feel uncomfortable with people living with HIV in the workplace and that many (32%) remain uniformed about HIV in general. Results also indicated that many employers questioned the integrity of HIV positive employees who do not disclose their status, and acknowledged participating in involuntary disclosure and breaches of employee confidentiality (Axiome Marketing, 2009). Tammi (1991) found that, despite these widespread concerns, only 10% of U.S corporations had policies that address HIV in the workplace. A Canadian survey of 1400 people living with HIV revealed slightly better results, with 23% of respondents reporting workplaces that had HIV policies or support programs in place (Canadian AIDS Society, 1998).

Other authors have expressed concern over a lack of reasonable workplace accommodations, many of which are cost effective and easily implemented. A variety of affordable accommodations have been found to facilitate employment for people living with HIV. These include flexible work schedules, part time work, time off for medical appointments and reassignment to less physically demanding jobs (Brooks & Klosinski, 1999; Conyers, 2005; Ferrier & Lavis, 2003; Walch et al., 2005). The consequences of not providing such accommodations can be substantial, as poor working conditions and a lack of accommodation

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cause increased stress among people living with HIV and have been identified as an independent risk factor for employment loss (Dray-Spira et al., 2006).

As indicated earlier, The Canadian Charter of Rights and Freedoms and the Canadian Human Rights Act prohibit discrimination based on physical or mental disability (Galarneau & Radulescu, 2009). Despite this important protection, workplace discrimination continues to be a major concern for people living with HIV (Adkins, 2002; Brooks et al., 2004; Canadian AIDS Society, 1998; Caulfield et al., 1994; Ciasullo & Escovitz, 2005; Dray-Spira et al., 2007; Hunt et al., 2003; Timmons & Fesko, 2004; Walch et al., 2005). Using survey methods, Brooks et al. (2004) sampled 757 people living with HIV in the U.S; of those, 66% identified workplace discrimination as a significant barrier preventing their involvement in the labour force. After conducting several quantitative studies (Conyers & Boomer, 2005; Conyers, Boomer, & McMahon, 2005; Conyers & Rumrill, 2005) documenting and comparing the incidence of workplace discrimination against people living with HIV in the U.S., Conyers (2005) concluded, "to the extent that workplace discrimination is a behavioural manifestation of negative attitudes and stigmatization, the theory that deeper levels of both are applicable to people living with HIV appears to be supported" (p.174). This has also been substantiated within Canadian jurisdictions. In a 2009 Quebec study, 38% of employers surveyed indicated that they would avoid hiring a person with HIV citing fear of absenteeism and a general fear and unease with HIV (Axiome Marketing, 2009).

Fear and anticipation associated with experiencing discrimination in the work place is common and negatively influences an individual's decisions regarding employment (Brooks et al., 2004; Dray-Spira & Lert, 2007; Hunt et al., 2003). In qualitative studies, Caulfield et al. (1994) and Glenn et al. (2003) explored the disclosure patterns of people living with HIV. They

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found that many individuals who disclosed their HIV status experienced discrimination in the

workplace and in hiring practices, and that fear, stigma, and negative attitudes in the workplace

thwarted disclosure of HIV status among many individuals looking for employment.

Consequently, many people living with HIV conceal their status (Glenn et al., 2003) and many

experience high levels of stress related to disclosure of their HIV status in the workplace (Brooks

et al., 2004; Caulfield et al., 1994; Escovitz & Donegan, 2005; Hyduk & Kustowski, 2003)

Several authors suggest relevant and proactive workplace policy structures as strategies

for creating supportive workplace environments and facilitators of successful labour force

participation. Workplace policies and a structured approach may alleviate common fears

regarding stigma and disclosure (Gadd & Goss, 1997). Likewise, several studies recommend

workplace policies that address confidentiality, benefits programs, and reasonable

accommodation (Bell-Rowbotham, 1997; Booth, 1993; Gadd & Goss, 1997; Hyduk &

Kustowski, 2003; Tammi, 1991).

2.5.4 Public Policy and Income Supports

Many people living with HIV in Canada rely upon federal, provincial, and private sector

income support policies and programs to provide them with a sustainable income. As indicated

earlier, the programs commonly involving those living with HIV include the Canada Pension

Plan disability program (CPPD), Employment Insurance sickness benefits, private long term

disability insurance benefits, and provincial social assistance benefits. These programs are

perhaps the single most important provision available to people living with HIV at the public

policy level. The literature suggests that multiple issues related to income maintenance and

insurance coverage are still of critical concern.

Those individuals who are successfully employed have often had to choose between the security of public and private income supports and the risks associated with participation in the labour force. These risks include the potential loss of public health and social benefits and often create a disincentive to work (Brooks & Klosinski, 1999; Escovitz & Donegan, 2005; Ferrier & Lavis, 2003; Hunt et al., 2003; Hyduk & Kustowski, 2003; McGinn, Gahagan, & Gibson, 2005). For those who have insurance coverage by a private sector insurer, return to work could entail losing their current disability benefits and drug coverage (Nixon & Renwick, 2003; Rosolen, 2002). Additionally, there is a lack of accessible information regarding disability benefit contracts and the possibility of inadequate coverage by employers (Brooks & Klosinski, 1999). In some cases, labour force participation raises the risk that possible low wages will not provide a reasonable level of income similar to that provided by social benefits (Paul-Ward, Kielhofner, et al., 2005). For those who are employed, the lack of portability of insurance coverage exists as a considerable barrier to career development, the result being that many people feel trapped in their current situations (Ferrier & Lavis, 2003; McReynolds & Garske, 2001; Rosolen, 2002).

Unfortunately, most income support policies and programs in Canada are designed for illnesses and disabilities that are experienced as chronic or single events; thus, they fail to adequately address the episodic nature of HIV. Ferrier and Lavis (2003) suggest that most of what is understood about return to work for people living with HIV pertains to factors that appear to explain short term disability rather than episodic illness. This leads to an inadequate fit between most mainstream programs and policies and the lived experience of those persons living with HIV (Worthington, O' Brien, et al., 2009). Additionally, the programs, policies, and legislation that influence labour force participation for people living with HIV are broadly characterized by fragmentation and a lack of integration. In one Canadian study, Maticka-

Tyndale (2002) concluded that existing workplace and government policies impede labour force participation for people living with HIV who have recovered from serious illness and are now willing to work. Policy fragmentation makes it difficult for people living with HIV and service providers to understand, let alone navigate the complex and contradictory network of programs and policies put in place by governments at the provincial and federal level (Anderson & Brown, 2005; Canadian HIV/AIDS Legal Network, 2005). Canadian legislation designed to protect the rights of disabled workers is vague, lacks standards, and relies on the subjective interpretation of employers to provide "reasonable accommodation" (Hyduk & Kustowski, 2003; Vezina, 2004). Programs and policies are seldom aligned with the episodic nature of HIV, and navigating the maze of complex rules and programs is a distinct and frustrating barrier for people living with HIV (Paul-Ward, Kielhofner, et al., 2005). A need for additional legislation prohibiting discrimination and protecting disclosure (Hyduk & Kustowski, 2003; Vezina, 2004) is raised by several authors as is the need for research and political advocacy to address the debilitating effect of Canadian policies (McReynolds, 2001). A lack of integration between federal and provincial income support policies and differences across jurisdictions create difficult barriers for people living with HIV who are managing vocational transitions (The Canadian Working Group on HIV and Rehabilitation, 2000)

2.5.5 Social Structural Factors

The social phenomenon of HIV exists at the intersection of multiple systems of oppression and institutionalized discrimination (Paton, 1990). Regardless of the jurisdiction, the HIV virus has consistently been coupled with fear, social inequity, and discrimination (Silversides, 2003). This social and historical reality has a significant effect on labour force

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participation for people living with HIV as several environmental and structural factors contribute negatively to the social context surrounding the issue.

Due to inadequate public income supports many people living with HIV subsist in precarious financial situations, suffering poverty and low socioeconomic status (Ferrier & Lavis, 2003; Gillies, Tolley, & Wolstenholme, 1996; Grierson, Pitts, & Misson, 2005). In addressing this issue, Escovitz (2005) concluded that successful employment may be an issue of greater relevance to those living with HIV who are poor and economically vulnerable specifically because they have fewer alternate resources and opportunities. The prevailing economic climate and a competitive labour market have a primary influence on employment processes for those living with HIV. Poor economic conditions can create an uncertain job market (Maguire et al., 2008; Paul-Ward, Braveman, et al., 2005), lack of resources for HIV employment services (Ciasullo & Escovitz, 2005), and conditions of vulnerability for people living with HIV who are interested in labour force participation.

Regrettably, increased unemployment has consistently been associated with the social and demographic characteristics of people living with HIV, including gender, race, and mode of transmission (Hoffman, 1997). Several quantitative studies have demonstrated that socio-demographic factors remain independent of health factors in determining unemployment, indicating that social status is as important to unemployment as an individual's physical health (Dray-Spira et al., 2007; Fogarty, Zablotska, Rawstorne, Prestage, & Kippax, 2007; Hoffman, 1997). A range of studies have further documented the detrimental impact of homophobia (Adkins, 2002), gender discrimination (Solomon & Wilkins, 2008), immigration and racism (Burns, Young, & Maniss, 2007; Joyce, Goldman, Liebowitz, Alpert, & Bao, 2005; Vidrine,

Amick, Gritz, & Arduino, 2003), and the stigmatizing nature of HIV (Breuer, 1998; Brooks &

Klosinski, 1999; Dray-Spira et al., 2007) on those individuals who are in the labour force.

Further complicating these issues are the adverse living conditions faced by many people

living with HIV. These include homelessness or unstable living situations (Escovitz & Donegan,

2005; Paul-Ward, Kielhofner, et al., 2005), poor access to transportation (Hergenrather et al.,

2004; Martin, Chernoff, & Buitron, 2005) and a lack of access to child care (Maguire et al.,

2008; Solomon & Wilkins, 2008); all issues that have critical implications for labour force

participation. Also, for some the high costs of medications and unequal access to medication

exist as barriers to sustained employment (McFarland, Chen, Hsu, Schwarcz, & Katz, 2003;

Rosolen, 2002).

2.5.6 Vocational Services for People Living With HIV

Longitudinal research has demonstrated poor employment outcomes for people living

with HIV following diagnosis, with some studies reporting less than 15% of participants

managing to maintain persistent work (Ezzy et al., 1999; Rabkin, McElhiney, Ferrando, Van

Gorp, & Lin, 2004; Van Gorp et al., 2007). Despite multiple barriers, with employment specific

support services, people living with HIV can be helped to work (Lee & Chan, 2005; Martin et

al., 2006; Paul-Ward, Braveman, et al., 2005). The HIV and employment literature has begun to

confirm that vocational support programs can provide benefits to people living with HIV and

lead to better employment outcomes.

For instance, Kielhofner et al. (2004) evaluated the outcomes of a community vocational

program for people living with HIV; of the 90 participants, 60were able to achieve their

vocational goals following participation in the program. Martin et al. (2006) utilized a quasi-

experimental design to demonstrate that those in vocational interventions were more likely to

return to work than those in comparison groups. Others have reported strong indicators that successful employment for people living with HIV is associated with receiving vocational counselling (Escovitz & Donegan, 2005; Lee & Chan, 2005).

Generally, employment services have been found to assist people living with HIV in becoming more psychologically prepared for employment and by facilitating their adjustment to the workplace (Conyers, 2004b; Kielhofner et al., 2004; Martin et al., 2006). Bowyer (2006) demonstrated how programs utilizing a holistic, strengths based, and individualized approach to vocational skill development can support successful labour force participation for people living with HIV. This emphasis on individualized skill development is supported through other studies documenting effective vocational strategies for working with people living with HIV (Brooks & Klosinski, 1999; Escovitz & Donegan, 2005; McReynolds & Garkse, 2001). Peer support models that provide opportunities to connect with other people living with HIV from a similar background are also recognized in the HIV and employment literature as providing unique benefits to people living with HIV (Berry & Hunt, 2005; Conyers, 2004b; Griffin, 2005).

Also valuable is vocational counselling to support job related problem solving (Escovitz & Donegan, 2005). Support in managing disclosure, benefits counselling, and assistance in negotiating workplace accommodations are critical areas where people living with HIV may require ongoing support from a vocational specialist. (Allen & Carlson, 2003; Escovitz & Donegan, 2005; Worthington, O'Brien, Zack, Popiel, Oliver, & McKee, 2010). Additionally, the presence of a mentor in the workplace is effective in supporting people living with HIV to sustain ongoing employment (Breuer, 1998). Service integration, collaboration, and public policy advocacy are areas of macro practice that are best integrated into HIV specific vocational support programs (McReynolds & Garske, 2001; Paul-Ward, Kielhofner, et al., 2005).

Subsequent formal and informal social support at the community level is requisite to assist people living with HIV as they address employment related concerns. Many individuals require supplementary community and social services to address issues not covered by vocational support programs. Timmons (2004), demonstrates that many people living with HIV use personal supports before professional resources for discussion of employment-related issues. Others have presented evidence highlighting the importance of a stable partnership or family support in maintaining successful labour force participation (Jia et al., 2004; Sendi et al., 2004). In situations where this is lacking, formal supports such as crisis intervention, case management, and counselling can be extremely beneficial to individuals trying to manage their employment concerns (Husbands et al., 2007). Increased availability of community resources can also facilitate successful employment. Supportive housing, benefits counselling (Brooks & Klosinski, 1999), heroin prescription programs (DeBeck et al., 2007), and community supports for newcomers and immigrants are advocated for by many authors as essential in supporting labour force participation within the diverse communities affected by HIV.

2.5.7 Impact and Outcomes of Employment for People Living with HIV

Unfortunately, relatively little research knowledge exists regarding the outcomes of labour force participation and the impact employment has on people living with HIV. Understandably, many people living with HIV approach employment with a degree of ambiguity, often due to fears that workplace stress will cause negative health effects (Brooks et al., 2004; Glenn et al., 2003). To date, the research literature identifies mainly positive health and social benefits associated with labour force participation (Rueda et al., 2012). Several quantitative studies report employment as a strong predictor of higher health related quality of life; concluding that employed people living with HIV experience higher physical functioning,

slower disease progression and better perceived general health (Burns et al., 2007; Cowdery & Pesa, 2002; Dray-Spira et al., 2006; Huba et al., 2000; Sowell et al., 1997). The social benefits of employment have also been demonstrated in the literature and may include an increased sense of well-being and belonging, a stronger sense of personal identity and improved self- esteem (Conyers, 2004b; Escovitz & Donegan, 2005; Hergenrather et al., 2004).

2.5.8 Theoretical Understandings Guiding Labour Force Interventions for People Living with HIV

Valid theory is essential to creating and informing effective, vocational interventions for people living with HIV. Conceptual work on this issue is in its infancy, having only commenced in the last decade. Nevertheless, a review of the HIV employment literature identified several frameworks that have contributed towards conceptualizing the employment experiences of people living with HIV. These investigations draw from and expand upon several formal theories of vocational development and disability and are interdisciplinary in nature. In sum, the HIV conceptual literature draws from a variety of traditions including social cognitive career theory, ecological perspectives, the transtheoretical model, the theory of planned behaviour, and other guiding theories in the vocational rehabilitation field. In the following discussion, these theoretical influences are briefly defined and HIV related inquiry is described (with figures where possible).

2.5.8.1 Social Cognitive Career Theory

The field of vocational psychology can trace its early influences to the work of Frank Parsons (1909) who shifted popular understandings of work and employment by introducing the notion that individuals choose vocational paths. Since that time the field has drawn heavily from developmental psychology and social learning theory, and maintained a primary focus on

developing theories that address occupational choice and performance in work settings (Hackett et al., 1991). Among contemporary understandings of vocational behaviour, social cognitive career theory has gained widespread application.

Drawing on Bandura's (1986) pioneering work in social learning theory, social cognitive career theory posits that "personal, contextual, and experiential factors are responsible for shaping experiences that lead to self-efficacy beliefs, career goals, and outcome expectations, which subsequently lead to career interests and choices" (Lent as cited inWerth, Borges, McNally, Maguire, & Britton, 2008a, p. 28). Emphasizing concepts such as "reciprocal determinism", these theories tend to focus on an individual's potential to alter and construct their social environments and in doing so they have tended to privilege human agency over structural determinism (McAlister, Perry, & Parcel, 2008; Viswanath, 2008). Key concepts include outcome expectations (beliefs about the likelihood and value of the consequences of behavioural choices), self-efficacy (beliefs about personal ability to perform behaviours that bring desired outcomes), collective efficacy (beliefs about the ability of a group to bring about desired outcomes), and observational learning (learning to perform new behaviours by exposure to interpersonal displays of them) (McAlister et al., 2008, p. 171). Originally developed for mainstream populations, social cognitive career theory has inspired early conceptual work being done on return to work for people living with HIV.

For example, drawing on social cognitive career theory, Braveman et al. (2006) explored the narratives of men living with HIV. This work contributed several relevant concepts to the HIV employment literature, stressing the importance of occupational identity, occupational competence, and occupational settings (environment) in supporting people living with HIV to

address employment. This further established the importance of client interactions with environmental constructs as part of vocational transitions (Braveman, Kielhofner, et al., 2006).

Also from this perspective, and incorporating a social model of disability, Paul-Ward et al. (2005) described how community-based research contributed to the development and implementation of employment services for people living with HIV. Describing how barriers at the community or societal level can impose limitations on the individual, this study advocates for eliminating these barriers and the creation of proactive policies in order to reduce disability (Paul-Ward, Braveman, et al., 2005). Additionally, Kielhofner et al. worked with the Employment Options program to develop and evaluate community vocational services for people living with HIV in Chicago. Participatory action research strategies were used in conjunction with social cognitive career theory to examine and improve the program as it unfolded (Kielhofner et al., 2004). They found that involvement in the program was closely associated with positive occupational identity and successful employment outcomes, thus supporting the use of social cognitive career theory in achieving sustainable and successful vocational outcomes for people living with HIV (Kielhofner et al., 2004).

Social cognitive career theory has had some success in informing vocational programs for people living with HIV and contributing some useful concepts for work with individuals particularly the idea of occupational identity, self-efficacy and their importance in vocational transitions. Nevertheless this approach is narrow in scope. It focuses largely on intrapersonal constructs and has failed to respond to the social structural issues identified by people living with HIV, including the stigma and discrimination so prevalent in workplace environments.

<u>2.5.8.2 Ecological Perspectives</u>

Ecological perspectives of career development also inform HIV employment theory. First proposed by Urie Brofenbrenner (1979), "ecological models emphasize the environmental and policy contexts of behaviour while incorporating social and psychological influences" (Sallis, Owen, & Fisher, 2008, p. 465). Within ecological models, social environments are seen as causing social problems and issues, as opposed to personal deficits (Maton, 2000). Analogous to social cognitive career theory, this perspective suggests that employment factors are determined by the interaction of intrapersonal, interpersonal, organizational, community, and policy constructs (Szymanski & Hanley-Maxwell, 1996). Thus, ecological models involve reciprocal transactions between the individual and their environment (McLeroy, Bibeau, Steckler, & Glanz, 1988). Ecological perspectives better accommodate issues related to ethnicity, race, and gender and include a critical analysis of the power dynamics involved in transactional processes (Ungar, 2002). The influence of ecological models is evident on some of the prominent, HIV employment frameworks developed within the research literature.

In a landmark Canadian study drawing on an ecological perspective, Ferrier and Lavis (2003) used qualitative methods to identify psychosocial factors effecting the return to work process for people living with HIV. In depth interviews and grounded theory data analysis were used to explore the risks and barriers of return to work (Ferrier & Lavis, 2003). Emerging themes included the benefits, risks and barriers to return to work for people living with HIV (Ferrier & Lavis, 2003). While giving voice to research participants, these data were also used to generate an ecological model of return to work that highlighted the importance of contextual factors and the strategies people living with HIV employed in addressing them while attempting a return to work. This model is represented in a logic diagram (Fig 2.1) with "considering return to work" as

the central category. Three other contributing components include causal conditions (improved

health and cultural norms about work), strategies employed, and their consequences. The social

context (insurance plans and workplace factors) and intervening conditions are seen to influence

the central phenomenon.

Fig. 2.1 A Model of Return to Work for People Living With HIV
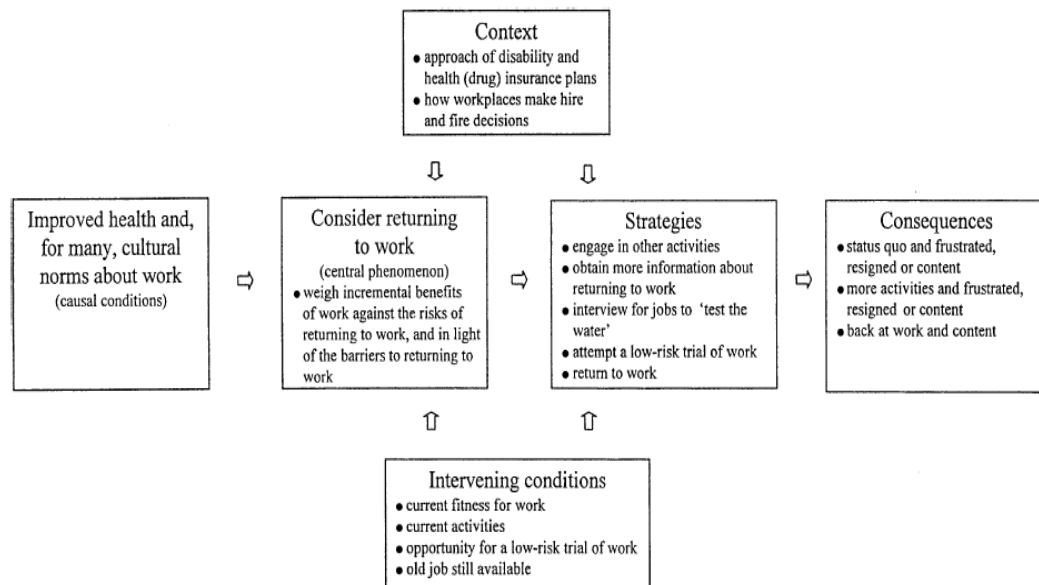
(Ferrier and Lavis, 2003)

Conyers (2004a), also utilized grounded theory to develop a conceptual understanding of

the career development factors and processes experienced by people living with HIV, which took

the form of an ecological model. She identified three main themes related to HIV and

employment: impact of HIV/AIDS, motivation to work, and barriers to employment. She

expanded upon the five constructs in the ecological model to create a better fit suggesting that

mediating factors such as vocational identity also play a significant role (Conyers, 2004a). Her

data suggest that the use of an ecological approach in rehabilitation planning would prove

effective.

Recognizing the need for integrative work, Maguire et al (2008), used community-based research and grounded theory to identify the employment related concerns of a large sample of people living with HIV. Ninety-three people living with HIV in the U.S participated in a series of focus groups exploring their feelings and experiences towards labour force participation. These data subsequently informed a dynamic, bi-directional model (Fig. 2.2) that highlighted the role of contextual and person level factors in three domains; health, employment and community (Maguire et al., 2008). In this model, the work experiences of people living with HIV are conceptualized as a group of interrelated components. Employment experiences are reflected in the mutual influences of contextual and internal factors as people living with HIV move around each domain. Priority focus is given to individual, psychological constructs such as stress-related and adaptive responses. Noting that counselling psychologists have traditionally not engaged in advocacy on behalf of marginalized populations, they concluded by recommending a social justice approach and increased partnership and integration with community-based organizations (Maguire et al., 2008).

Figure 2.2 Factors Influencing the Work Experiences of People Living With HIV
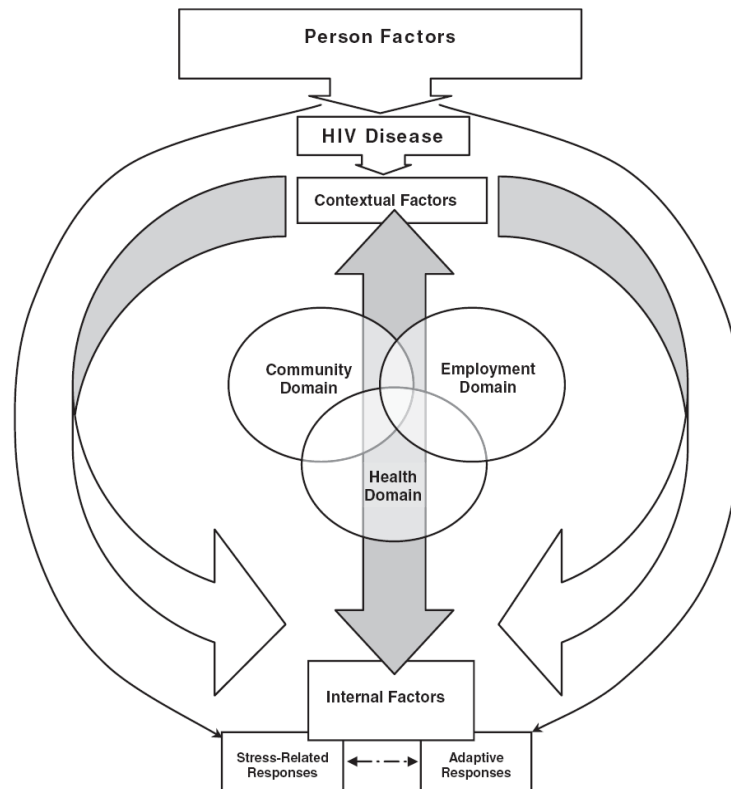
Factors Influencing the Work Experiences of People Living With HIV. Maguire, C. P., McNally, C. J., Britton, P. J., Werth, J. L., Jr., & Borges, N. J. (2008) Copyright SAGE Publications. Reprinted with permission of SAGE Publications

Ecological models appear to be a promising approach to HIV and vocational rehabilitation as they effectively conceptualize the dynamic interaction between personal, community, and structural factors. Additionally, ecological approaches to career development have been used with other diverse populations. Acknowledging that no one theory of career development can adequately address all forms of disability, Szymancki, and Hanley-Maxwell (1996) developed an ecological model of career development for people with developmental

disabilities. Additionally Cook et al (2005) suggested an ecological perspective of career development for working with women from diverse racial and ethnic backgrounds.

The drawbacks of these models is that they tend to be broad, often lacking detail, and at times fail to articulate direct, measurable relationships. Furthermore several authors have noted that even with ecological models, sometimes scant attention is paid to a critical conceptualization of the social environment or to issues of power and oppression (McLeroy et al., 1988; Ungar, 2002). Nevertheless, work from this perspective has broadened the field and provided a new focus on overlooked areas of inquiry and advocated for a social justice agenda within counselling psychology.

2.5.8.3 Transtheoretical Models

The transtheoretical model (TTM) suggests stages as a means of integrating processes and principles of change across several major theories and disciplines (Prochaska, Redding, & Evers, 2008). It outlines a general process by which people achieve change by progressing through a series of defined stages. In addition to ten processes (consciousness-raising, dramatic relief, self-reevaluation, environmental reevaluation, self-liberation, social liberation, counter conditioning, stimulus control, contingency management, and helping relationships) this widely applied theory describes six stages of change as its core constructs: pre-contemplation, contemplation, preparation, action, maintenance, and termination (Prochaska et al., 2008, p. 101). It also incorporates the self-efficacy construct in supporting individuals to make behavioural changes and suggests that individuals should receive interventions appropriate for their stage in order to support behaviour change (Prochaska et al., 2008; Viswanath, 2008). The transtheoretical model has been adapted by two authors for use in vocational work with people living with HIV.

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Goldblum and Kohlenberg (2001) tailored the stages of change in the development of their client focused model of considering work (Fig. 2.3). This model is influenced by the principles of consumer directed empowerment, "a process in which one defines and achieves goals based on a foundation of knowing and valuing oneself" (Goldblum & Kohlenberg, 2005, p. 116). The model describes the interplay between four domains of influence (medical, financial/legal, psychosocial, and vocational) and articulates a nonlinear, four phase, vocational decision-making process (contemplation, preparation, action, resolution). By taking into account all four domains, people living with HIV increase their ability to make well informed decisions and successfully manage vocational transitions. This approach was associated with a reduction in vocational concerns and progress towards vocational goals (Goldblum & Kohlenberg, 2005).

Figure 2.3 The Client Focused Model of Considering Work
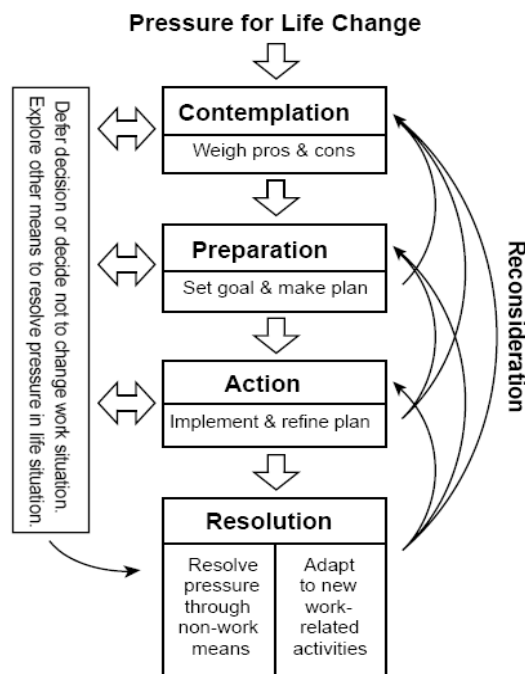
(Goldblum and Kohlenberg, 2001)

Additionally Martin et al. (2004) used motivational interviewing techniques to assist people living with HIV to progress through the stages of change and achieve their goals of returning to work. This approach was simultaneously evaluated and shown to be an effective approach in supporting people living with HIV to return to work (Martin, Arns, Chernoff, & Steckart, 2004).

2.5.8.4 The Theory of Planned Behavior

The theory of planned behaviour explores connections between attitudes and behaviour. The theory assumes that attitudes toward behaviour, norms, and behavioural control, together shape an individual's intentions and behaviours (Montano & Kasprzyk, 2008). Here, the influences of beliefs, attitudes, resources, and social pressure are explored for their impact on the likelihood of performing a specific behaviour (Hergenrather, Rhodes, & McDaniel, 2005). Research conducted in this area has identified systematic methods to identify the issues that are most important in an individual's decision making process in order to target these for subsequent intervention when necessary (Viswanath, 2008).

Hergenrather (2001, 2006, 2005) utilized this approach in multiple studies exploring the vocational decision making processes of people living with HIV. As part of a community-university partnership, photovoice methodology was used to identify influences upon the employment seeking behaviour of people living with HIV. In addition to identifying advantages, disadvantages, facilitators, and impediments to employment; this study contributed a definition of employment developed from participants' perspectives. This definition, "a societal expectation that rejuvenates self-worth and pride, increasing ones skills abilities and confidence" (Hergenrather et al., 2006, p. 248) is at the core of the employment decision making model also developed from these data (Fig. 2.4). The study suggested the utility of using the theory of planned behaviour to identify relevant employment beliefs for the development of interventions

to enhance job placement outcomes for people living with HIV. Hergenrather also used the

theory of planned behaviour to explore the job-placement decisions of vocational counselors

working with people living with HIV, establishing that negative attitudes and values about

people living with HIV held by vocational professionals influenced their decision making

(Hergenrather, 2001).

Figure 2.4 The Employment Decision Making Model
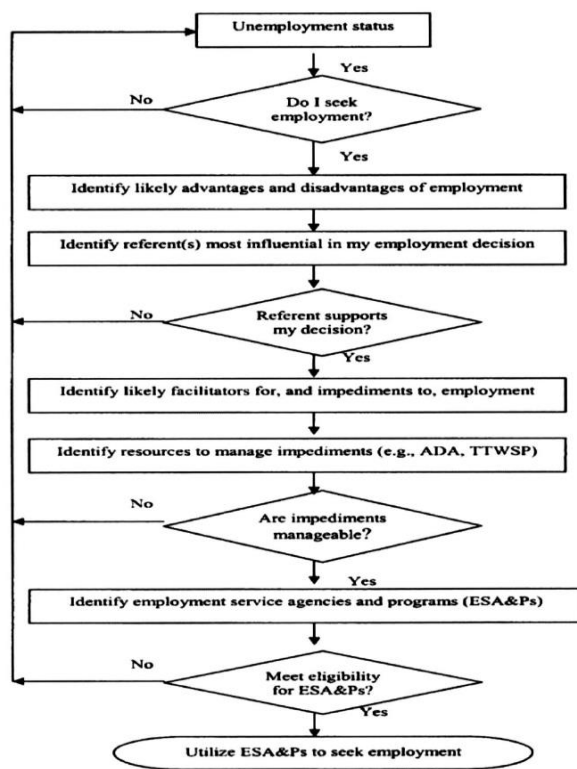
The Employment Decision Making Model, Hergenrather, K. C., Rhodes, S. D., & Clark, G.
(2006). Copyright Guilford Press. Reprinted with permission of The Guilford Press

Transtheoretical models and the theory of planned behaviour have proved useful in

conceptualizing and addressing relatively narrow processes such as the return to work process

and other decision making processes. They have, however, been limited in their application to

the broader processes and structures that characterize labour force participation for people living

with HIV. These models have been eclipsed in the literature by other approaches as needs in the field suggest a more integrative approach.

2.5.8.5 Rehabilitation Perspectives

A variety of perspectives from the field of rehabilitation have been used to conceptualize labour force participation for people living with HIV. For instance, Hwang (2003) used case studies to explore the effectiveness of the World Health Organization's International Classification of Functioning (ICF). The ICF provides a universal classification system to describe and measure an individual's disabling conditions. The framework views disability as impacting three levels: body, individual and society (Hwang & Nochajski, 2003). Although it claims to be effective cross culturally, a narrow focus on medical concepts means that this framework might not be useful in an HIV context or outside of a clinical setting.

Occupational therapists Fish and Rudman (1998) employed chart review methods to identify models for working with people living with HIV. They expanded upon Kielhofners' Model of Human Occupation (MOHO) to demonstrate its relevance in rehabilitation work with people living with HIV. This resulted in a holistic and occupation centred model which outlines the role for occupational therapy in supporting people living with HIV (Fish & Rudman, 1998). This model is noteworthy for the extent to which it acknowledges the importance of the social environment. In a similar exercise, Reid et al. explored Schlossberg's transitions theory as a framework for understanding the return to work issues of people living with HIV. This approach identified seven variables from Schlossberg's model that characterize return to work, "transition: trigger, timing, source, role change, duration, previous experience with a similar problem and concurrent stress" (Reid, Leierer, & Millington, 1999, p. 59). Both models serve as practical guides for rehabilitation professionals interested in working with people living with HIV.

2.5.8.6 A Conceptual Framework of Labour Force Participation for People Living with HIV in Canada

Worthington et al. (2010) used scoping review methodology and community-based research methods to develop a conceptual framework of labour force participation relevant to a Canadian context. This broad, interdisciplinary framework is based on a review of the research and grey literature, and is further informed by interviews with key stakeholders (service providers, insurers, employers and policy makers) and focus groups with people living with HIV. The framework incorporates six key components related to labour force participation for people living with HIV: the meaning of work, characteristics of work, contextual factors that influence employment, barriers and facilitators to employment (issues related to the personal, employment and public policy domains), strategies and supports for entering, returning to and/or sustaining employment and potential outcomes of labour force participation (risks/benefits for individuals, and costs/benefits for employers, governments, and insurers). Interdisciplinary in nature, the framework incorporates material from a wide range of perspectives contributing an integrative approach to the issue of labour force participation for people living with HIV. The strength of this framework lies in its comprehensive and integrative approach to the issue. Nevertheless, it also contains several conceptual gaps and areas where evidence is lacking, notably in areas related to public policy and contextual factors. Further, while its breadth makes it applicable to many settings, it also means that it is not appropriate as the foundation for an intervention model.

2.6 Summary

In summary, the relevant literature on HIV and employment was synthesized into several broad themes that include the motivation to work, health factors, workplace environments, public

policy, social structural factors, vocational services and theoretical understandings guiding labour force interventions for people living with HIV. Development of this literature has followed a dynamic course and involves contributions from several theoretical approaches representing a variety of research paradigms. Thus the field benefits from an interdisciplinary approach and a variety of distinct conceptual lenses. In general, the strengths of the HIV and employment literature has been an approach that increasingly engages diverse methods including constructivist inquiry and participatory methodologies. As is evident in other forms of HIV research, knowledge from a single perspective is broadening to include inter-disciplinary approaches that contribute to a broader understanding of HIV and employment (Auerbach, Parkhurst, Caceres, & Keller, 2009).

Additionally, there are several limitations associated with the employment research on labour force participation for people living with HIV. The HIV and employment literature has been critiqued for oversampling among a homogenous group of clients (Werth, Borges, McNally, Maguire, & Britton, 2008a). Due to the epidemiology of the disease much of the research on HIV and employment has been conducted with samples of gay men in large urban settings. Several authors have identified a need for more HIV and employment research that effectively considers issues such as race, gender, addictions, poverty, and mental health (Conyers, 2008; Werth, Borges, McNally, Maguire, & Britton, 2008b). Thus while traditional concepts drawn from vocational psychology may be useful in providing a basic understanding of vocational processes, they often do not apply easily to individuals from a variety of social locations or marginalized populations. Consequently, emerging research on HIV and employment has begun focusing on the employment experiences of women, immigrants and racialized people living with HIV and has started to explore an individual's interaction with the

vocational environment and context. In addition this literature has tended to focus on the return to work process rather than on those who have successfully maintained employment while managing HIV.

The existing labour force participation literature provides needed evidence related to vocational barriers and challenges facing many people living with HIV. Nevertheless there is a growing need for research that examines employment facilitators, that reflects the episodic nature of HIV, and that explores their impact on employment processes (Worthington, O'Brien, Zack, McKee, & Oliver, 2012). Additionally, more research is required into vocational rehabilitation for people living with HIV and the types of interventions that could be effective in supporting those individuals who choose employment. Research that assesses the efficacy of existing vocational programs in the Canadian context is a gap as is research on public policy and income support policies that shape employment processes. Research that addresses these factors would provide additional evidence to support community service providers in the planning and provision of effective vocational services for people living with HIV.

This section has contributed a synthesis and evaluation of the current research on HIV and employment. A comprehensive and integrated body of research and theory addressing labour force participation is a critical tool for developing relevant employment programs and policy (Conyers, 2008). Accordingly, a deeper understanding of labour force participation and the factors that support vocational success and associated well-being among people living with HIV is a critical gap in the Canadian context and a recommended focus for future research. As such, this study endeavours to fill this need by investigating the experiences of people living with HIV who are working successfully and the factors that influence their success.

CHAPTER THREE: METHODOLOGY

3.1 Introduction

This qualitative research investigation explores the perspectives of people living with HIV who have successfully maintained participation in the labour force, and the goal of this study is to develop a conceptual framework identifying the processes and structures that shape these experiences. Given the nature of the research question and the need to generate theory that closely reflects the lived experiences of people living with HIV, a qualitative inquiry paradigm was selected to guide this dissertation research. In any naturalistic research inquiry a thoughtful and thorough strategic framework is essential in providing direction to the research and in guiding an investigator's decisions (Patton, 2002). This chapter begins by providing the rationale for the study methodology, specifically, the use of community-based research principles and constructivist grounded theory. The second section describes the research design including sampling, data collection, and data analysis procedures. In the third section, ethical considerations are outlined and issues related to the trustworthiness of the study are discussed.

3.2. Rationale

Qualitative research is defined through several important criteria including an interpretive approach, the studying of social problems in their natural settings, the use of narrative, and an emphasis on holistic and complex processes (Creswell, 1998; Denzin & Lincoln, 2008). The qualitative approach is comprised of a series of interpretive practices "that make the world visible" (Denzin & Lincoln, 1994, p.3). As such, the qualitative research paradigm involves understanding how social experiences are created and given meaning (Creswell, 1998; Denzin & Lincoln, 2008).

Qualitative research is an appropriate approach for exploring the employment processes of people living with HIV as it allows for in-depth exploration of the experiences and perspectives of research participants (Lincoln & Guba, 1985). Additionally, in a field where up to 80% of the research literature comes from within the quantitative tradition (Worthington, O'Brien, et al., 2012) , a qualitative approach contributes additional descriptive and theoretical understanding of the issue and provides narratives that can better represent the diverse perspectives of people living with HIV. With these goals in mind, the dissertation research was conducted using a community- based research framework and grounded theory methods.

3.2.1 Traditions of Participatory Inquiry

Participatory research is an evolving paradigm subject to numerous interpretations. Rather than a method, participatory research is viewed as an orientation to inquiry, with many schools, theories, and practices (Reason & Bradbury, 2000). Labels attributed to participatory methodologies vary considerably and are often distinguished by the discipline of their contributors. Among them, action research, participatory action research, emancipatory enquiry, and community-based participatory research are common in the social sciences and health sciences literature (Israel, Schulz, Parker, & Becker, 1998). Regardless of their articulation, participatory methods share the common and interconnected goals of "research, action, and education" (Wallerstein & Duran, 2003, p. 30).

Participatory research epistemologies view knowledge making as rooted in everyday experience and tend to reject the researcher – subject division common to traditional positivist research (Park, 1993). Given this position, participatory researchers value real world knowledge and endeavour to participate in reciprocal collaborations with community members (Cargo & Mercer, 2008). As a result, community members are often involved in determining the research

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agenda and in planning, implementing, and disseminating the research (Wallerstein & Duran, 2003). Differing from established forms of scientific inquiry, a participatory research project may utilize a diverse range of study designs including qualitative, quantitative, or mixed methods approaches (Cargo & Mercer, 2008). Accordingly, research methods are often chosen based on he purpose of the study as well as the community setting and social context in which it is conducted (Israel et al., 1998).

The participatory paradigm is home to a broad range of specific methodologies that are situated on a continuum between transformative and pragmatic orientations. The differences between these two traditions can be characterized by several factors including the role of the community, the orientation of power within the research process, and the political objectives of the research (Wallerstein & Duran, 2003). Transformative methodologies, such as participatory action research, emerged from developing countries in the global south and emphasize collective research, critical consciousness, and the transformation of political and social structures (Rutman, Hubberstey, Barlow, & Brown, 2005). Conversely, pragmatic orientations are more common in western and developed countries, and emphasize the democratization of research through citizen participation, individual empowerment, and community capacity building (Flicker, Savan, Kolenda, & Mildenberger, 2008; Florin & Wanderson, 1990).Within this tradition, research is frequently initiated in order to solve community problems, improve program planning, or to inform the development of public policy (Minkler, 2000). Regardless of the categorization or the jurisdiction, participatory approaches typically embody a commitment to social justice and the concrete application of research findings (Reason & Bradbury, 2006).

3.2.2 Community-Based Research

A prominent method from within the pragmatic tradition is community-based participatory research. Championed by Dewey (1939) and Mead (1927/1964), the pragmatist philosophical tradition focuses on the interaction between individuals and the social world, links theory and action, and assumes that meanings emerge through practical actions to solve problems (Biesta & Burbules, 2003; Charmaz, 2006; Greenwood & Levin, 2005). Community-based participatory research is commonly used in health and social science research and has been described as "a collaborative approach to research that equitably involves all partners in the research process "… (it) has the aim of combining knowledge with action and achieving social change to improve health outcomes and eliminate health disparities" (Flicker, Travers, Guta, McDonald, & Meagher, 2007, p. 2). Within community-based participatory research, social change is measured in incremental steps through improvements in systems and organizations. Much work has been published regarding the values and assumptions of community-based participatory research (See Israel et al., 1998; Minkler, 2004; Minkler, Breckwith Vasquez, Mansoureh, & Petersen, 2008; Minkler & Wallerstein, 2008; Wallerstein & Duran, 2003). Some key principles that differentiate community-based participatory research from more established forms of research include the recognition of community as a unit of identity, facilitation of collaborative partnerships, promotion of co-learning, and the dissemination of knowledge to all partners (Israel et al., 1998).

Drawing upon the values and assumptions of community-based participatory research, community-based research is the principal form of participatory inquiry utilized in Canadian HIV social sciences research and is used extensively to inform public policy and effective community responses to the HIV pandemic. Between 2004 and 2007, the Canadian Institutes of

Health Research (CIHR) allocated over 9 million dollars to HIV community-based research collaborations between Canadian academics and community groups (Canadian Institutes of Health Research, 2009). Contributors from within the AIDS movement have helped to further articulate the principles of community-based research in an HIV specific context. Within the sector, community-based research has been defined as research "conducted by, for or with the participation of community members … community-based research aims to advance understanding and to ensure that knowledge contributes to making a concrete and constructive difference in the world" (Flicker et al., 2008, p. 106). Important principles of community-based research include a commitment to the community initiation of research, capacity building, varied research methods, joint data ownership, community relevance, social action, and ethical review (Flicker et al., 2007).

Community-based research is driven by an empowerment approach, a process whereby, "people, organizations, and communities gain mastery over their affairs" (Florin & Wanderson, 1990, p. 44). In the HIV sector, community initiation of research is a guiding principle and studies are frequently conceptualized according to the social and community context or the practice setting (Flicker et al., 2007). Moreover, community members, people living with HIV, and service providers are often involved in planning, implementing and disseminating the research (Wallerstein & Duran, 2003). As such, it is an effective methodology for use with critical and anti-oppressive theoretical frameworks. Cultural humility and critical attention to the history and context of communities are important strategies that enable participatory researchers to redress power imbalances and create respectful partnerships with communities (Fals-Borda & Rahman, 1991). Accordingly, community-based research processes are designed to create

conditions conducive to individual, organizational, and community growth and development (Cargo & Mercer, 2008).

3.2.2.1 Community-Based Research: Ontology and Epistemology

Fundamental to the goodness of fit between community-based research and the AIDS movement are the pragmatic philosophical foundations of the participatory world view. Ontology poses the question, "whether the reality to be investigated is external to the individual or the product of individual consciousness" (Poonamallee, 2009, p. 71). Participatory ways of knowing ground ontology within the concepts of interaction, relationship, and participation (Heron & Reason, 1997; Lincoln & Guba, 1985). Accordingly, the participatory world view articulates, a participative, subjective-objective reality which is co-created by the mind and "the given cosmos" (Guba & Lincoln, 2005; Heron & Reason, 1997, p. 277). Freire articulated the main premise of this ontology claiming that "the concrete reality is the connection between subjectivity and objectivity, never objectivity isolated from subjectivity" (Freire, 1982, p. 29). In short, reality does not exist out there in the real world but is actively created by researchers and community members. In this manner subject and object are considered interdependent and "participation is fundamental to the nature of our being, an ontological given" (Reason & Bradbury, 2006, p. 8).

A participative ontology provides grounding for the knowledge claims expounded in community-based research and for an expanded epistemology that supports a vision of social justice. This position includes recognition of experiential and practical ways of knowing and an acknowledgement that co-created findings are at best mediated and subjective (Guba & Lincoln, 2005; Heron & Reason, 1997). Although research findings are not considered final or absolute, the knowledge that is constructed through participatory inquiry may build a shared and

consensual understanding of an experience. This type of contextualized knowledge proves useful

to researchers and community members in initiating dialogue, identifying issues of concern, and

in reaching consensus about what social action is required (Wallerstein & Duran, 2003). In this

sense, participatory researchers and community members collaborate to better understand and

interpret their shared experience while simultaneously shaping their shared reality (Reason &

Bradbury, 2006).

3.2.2.2 The Greater Involvement of People Living with AIDS Principles

The principles of community-based research are closely aligned with the goals of social

justice movements that value the empowerment and increased self-reliance of historically

marginalized groups. Accordingly, community-based research in the AIDS sector incorporates

the greater involvement of people living with AIDS (GIPA) principles; a set of principles

guiding the meaningful and equitable inclusion of people living with HIV (International

HIV/AIDS Alliance & The Global Network of People Living with HIV, 2010). The principles

have been integrated throughout the AIDS movement in Canada with the goal of ensuring that all

HIV initiatives meaningfully involve people living with HIV.

Historically, AIDS activism radically challenged the dominance of established

knowledge production, leading to new and broader forms of AIDS knowledge construction

(Paton, 1990). A demand for full inclusion in all decisions affecting the lives of people living

with HIV has been a fundamental aspect of all forms of this activism. For instance, in 1983 the

Denver Principles offered, "a new way of understanding, and of integrating scientific data with

emotional realities" (Silversides, 2003, p. 43). These principles, developed by a caucus of people

living with HIV attending an international lesbian and gay health conference, challenged the

conceptualization of people living with HIV as merely victims and patients, asserting their right

to control their own health (Silversides, 2003). This early demand for self-determination led to the establishment of the GIPA principles. Adopted internationally at the 1994 Paris AIDS summit, the GIPA principles advocate for the full inclusion of people living with HIV in decision making regarding all forms of AIDS intervention including research (Travers et al., 2008). Since then, work conducted by community stakeholders has further articulated the importance of implementing the GIPA principles into the Canadian response. For instance the Ontario Accord (2011), created by representatives from Ontario AIDS service organizations, has emphasized a focus on inclusion, social transformation, and renewed accountability within the AIDS movement (Ontario AIDS Network, 2011). In a research context, the GIPA principles embody a recognition that the full participation of people living with HIV is critical in constructing research knowledge. Various complications and obstacles related to implementing the GIPA principles within AIDS service organizations have been documented and include issues related to the changing health of people living with HIV and tensions regarding stigma and disclosure (Cain, Collins, Bereket, George, Jackson, Li et al., 2014). Nevertheless, the community- based AIDS movement in Canada has promoted the full implementation of the GIPA principles within all research endeavours, demanding that academics share knowledge production with people living with HIV (Flicker et al., 2007). Over time these demands have culminated in a shift towards a participatory paradigm for AIDS research in the social sciences in Canada.

Given the historical construction of AIDS knowledge and the social and political values of the present movement, community-based research exists as an appropriate alternative to more established research paradigms. This dissertation capitalized on the strengths of community-based research approaches as a useful framework from which to explore the research question.

<u>3.2.2.2 Community-based Research and Grounded Theory</u>

Community-based research is a particularly good fit with grounded theory as it can contribute a strong set of values and principles to that method's focus on inductive theory construction and systematic approach to data collection and analysis. It is precisely these processes, grounded in a participative, subjective-objective ontology that makes community-based research a fertile and promising methodology for the AIDS movement and a relevant approach for this inquiry. Additionally, community-based research's focus on empowerment, collaboration, dialogue, critical reflection, and social justice constitute an excellent match with anti-oppressive social work practice and research.

3.2.3 An Overview of Grounded Theory

Within this community-based research framework, this investigation utilizes grounded theory, a qualitative research methodology that is primarily concerned with the study of social processes and human interaction and is well suited to studying new or emerging phenomenon (Dey, 1999; Glaser & Strauss, 1967). First articulated by Barney Glaser and Anselm Strauss (1967), grounded theory methods offered systematic sets of procedures to develop substantive theories of psychosocial phenomena (Draucker, Martsolf, Ross, & Rusk, 2007). Grounded theory offers guidelines for collecting and analyzing qualitative data resulting in the emergence of theories that are grounded in the lived experiences of research participants (Charmaz, 2006; Draucker et al., 2007). Commensurate with participatory approaches, much grounded theory draws from symbolic interactionism, a theoretical perspective that understands meaning as primarily defined and redefined through human interaction (Strauss & Corbin, 1998). Symbolic interactionism is governed by three central tenets: (a) human beings act on the basis of meaning; (b) meaning results from social interactions; and, (c) meanings are modified through an

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interpretive process (Blumer, 1969). The aim of a grounded theory study is to generate a theory or an "abstract analytical schema of a phenomenon that relates to a particular situation" (Creswell, 1998, p. 56). The resulting analysis emerges from the data and leads to theories that describe common issues for people in useful ways (Mills & Bonner, 2006).

Over the last four decades, grounded theory methodology has evolved in response to challenges from postmodernists and critical theorists. This is evident in the emergence of several new forms of grounded theory that hold conflicting epistemological and ontological assumptions (Annells, 1996; Charmaz, 2000; Clarke, 2003). Mills and Bonner (2006) describe three broad categories of grounded theory; traditional, evolved, and constructivist. Each differs according to its conceptual directions and its, "epistemological allegiances and methodological strategies" (Charmaz, 2008, p. 134).

3.2.3.1 Traditional Grounded Theory

Traditional grounded theory closely reflects the original theoretical positions of its founders, Barney Glaser and Anselm Strauss, as first articulated in *The Discovery of Grounded Theory: Strategies for Qualitative Research* (1967). The methodology draws upon symbolic interactionism, and pragmatism which "views reality as consisting of fluid, somewhat indeterminate processes and acknowledges multiple perspectives emerging from people's actions to solve problems in their world" (Charmaz, 2008, p. 128). As such the object of study is the action, interaction, and basic social processes of individuals (Creswell, 1998). In describing human processes, the analyst accounts for or explains the changes they observe in the world. This is often conceptualized in terms of steps, phases, or stages (Dey, 1999). On first discovery, grounded theory differed from established, positivist scientific methods which emphasized the testing of theory. Instead, grounded theorists built their analysis inductively, using multiple data

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sources and constant comparison (Milliken & Schreiber, 2001). In this manner the researcher creates concepts, categories, and frameworks from the ground up. The resulting analysis emerges from the data leading to theories that are effective in the field (Glaser & Strauss, 1967).

Constant comparative analysis is a critical distinction of grounded theory. During this process the researcher continually checks, questions, and interprets the data even while data collection is ongoing (Teram, Schachter, & Stalker, 2005). The method includes comparisons of data from individuals, incidents, and among and within categories (Charmaz, 2000). This is achieved through coding: " analytical processes through which data are fractured, conceptualized, and integrated to form theory" (Strauss & Corbin, 1998, p. 3). Coding allows the grounded theorist to attach labels to data and to sort them in ways that allow for comparison (Charmaz, 2006). Glaser and Strauss emphasized basic coding techniques whereby the researcher forms initial categories of information and then identifies the properties and dimensions of that category (Creswell, 1998). The result is an emerging set of concepts and categories; units of information representing certain phenomena (Creswell, 1998). From this method the researcher may create a theory that interprets and explains certain relationships between categories.

Another defining property of grounded theory is theoretical sampling. Embedded within the constant comparative process, theoretical sampling allows the researcher to recruit participants and/or texts that are best able to contribute to theory development (Glaser & Strauss, 1967). Grounded theorists would typically continue to recruit participants until they reach saturation, whereby no new theoretically relevant information is identified (Creswell, 1998). The concurrent processes of constant comparison, coding, and theoretical sampling contributes to the iterative and emergent nature of grounded theory methodology.

Traditional grounded theory has been identified as useful in conducting research into new or emerging phenomenon (Glaser & Strauss, 1967). Traditional grounded theorists are expected to approach their topic with very little pre-existing knowledge; although sensitizing concepts or existing ways of understanding the experience can be used as, "points of departure from which to study the data" (Charmaz, 2000, p. 515). Generally, grounded theorists aim to recruit more than 20 participants during frequent trips to the field (Creswell, 1998). Resulting theories are meant to "illuminate common issues for people in a way that allows them to identify with theory and use it in their own lives" (Mills & Bonner, 2006, p. 32). Broadly speaking, these qualities establish traditional grounded theory as a suitable methodology for social work research where there is a general expectation that theories will be generated from practice (Fook, 2002).

Traditional grounded theory was an innovative departure from other forms of qualitative inquiry; one that challenged the dominant status of quantitative methods and had lasting impact on research in the social sciences. It challenged many pre-conceived notions of qualitative methodologies including the existence of arbitrary divisions between theory and research, the necessity to separate data collection and analysis, and the assumption that qualitative methods could not create theory development (Charmaz, 2000).

Glaser and Strauss continued to articulate the methodology in a series of books and publications after the first book in 1967. Almost as soon as its basic tenets were established, grounded theory was contested. In a public and bitter split, Glaser and Strauss began advocating differing forms of grounded theory. As a result, the methodology evolved and expanded in order to include postmodern and critical epistemologies. Eventually, grounded theory evolved into what Charmaz (2008) described as, "not a unitary method but as a useful nodal point around which researchers discuss contemporary debates in qualitative inquiry" (p.128).

Traditional grounded theory methodology has been criticized as having an astructural bias, meaning that it has remained unconcerned with the influence of social and structural conditions on human action and does not account for historical, political, and cultural influences (MacDonald, 2001). Indeed, Glaser and Strauss conceived of structural issues as pre-conditions that individuals confront, existing as secondary to psychological processes (Dey, 1999). These factors contribute to the perception of traditional grounded theory as residing in the positivist tradition and viewing data as real in and of themselves (Charmaz, 2006). Certainly, the classic methodology is more likely to assume an external reality independent of an objective and unbiased observer/researcher; establishing it as a problematic approach for the complex social, political, and cultural terrain in which HIV research resides and inconsistent with the assumptions inherent in participatory inquiry (Charmaz, 2000).

3.2.3.2 Evolved Grounded Theory

What Mills and Bonner (2006) label as evolved grounded theory is a form of the methodology principally advocated by Anselm Strauss and Juliet Corbin. In further articulating this form of grounded theory methodology, Strauss and Corbin (1998) emphasized the importance of interpretative theories rather than explanatory ones (Charmaz, 2006). Shifting slightly from the positivistic assumptions of the traditional method, they acknowledged that it is impossible for grounded theorists to be completely objective and encouraged researchers to ensure that their biases do not overtly influence their interpretations (Strauss & Corbin, 1998).

Evolved grounded theory as articulated by Strauss and Corbin, attempts to build upon the basic processes identified in *The Discovery of Grounded Theory*. The main distinction is the development of a more sophisticated and prescriptive set of coding techniques. Strauss and Corbin offer several analytic tools to assist grounded theorists in coding and comparing data.

Three such tools include the flip-flop technique which encourages researchers to look at opposites to bring out new properties, the systematic comparison which evaluates an incident in the data with one from outside sources, and waving the red flag which assists analysts to identify situations where their bias is interfering with the data (Strauss & Corbin, 1998).

A defining feature of Strauss and Corbin's grounded theory are two additional techniques labeled axial coding and selective coding. Axial coding is, "the process of relating categories to subcategories; termed axial because coding occurs around the axis of a category, linking categories at the level of properties and dimensions" (Strauss & Corbin, 1998, p. 132). This technique broadened the analysis of a process to include not only the category but also the social interactions involved and their consequences (Charmaz, 2000). Selective coding is "the process by which all categories are unified around a core category" (Corbin & Strauss, 1990). Strauss and Corbin encouraged grounded theorists to consider the causal, intervening and contextual conditions that influence the core social process (Strauss & Corbin, 1998). As implied in these labels, causal or antecedent conditions are those that lead to the occurrence of a phenomenon; intervening conditions are those located in the broader structural context and contextual conditions are properties that impact the way the interaction unfolds (Dey, 1999). These techniques, along with other features of evolved grounded theory, brought a systematic quality to the method. Together these tools implied increased rigor and encouraged an emphasis on validity (or credibility) within qualitative methods.

Traditional forms of grounded theory analysis have been criticized for a lack of attention to social structure. Through introduction of their conditional matrix, Strauss and Corbin directed grounded theorists towards a consideration of the effects of social structure on the process under investigation. The conditional matrix is a diagram that maps the range of conditions in which a

phenomenon is rooted (MacDonald, 2001). A grounded theorist can use the matrix to identify structural factors that influence the central phenomenon. While a break from traditional symbolic interactionism, the conditional matrix still identifies basic social processes as the integral focus of the study and views structural conditions as secondary (Dey, 1999). Still, many perceive this tool as a true departure in grounded theory and consider that "the use of a conditional matrix by a theoretically sensitive grounded theorist researcher will most likely introduce issues of class, race, gender and the like" (Annells, 1996, p. 390).

With its focus on step-by-step procedures and increased validity, grounded theory appeared increasingly credible to funders and granting agencies. As a result it became widely used in mainstream social work and research in the social sciences. While popular, it was not without several critics. Among these was Barney Glaser who felt that Strauss and Corbin's use of prescriptive methods served to force preconceived questions and frameworks on the data (Charmaz, 2000). Several authors have also noted that although differences emerged between the two methods, both continued to mimic elements of quantitative research while endorsing a realist ontology and positivist epistemology (Charmaz, 2000).

3.2.3.3 Constructivist Grounded Theory

In articulating a vision of constructivist grounded theory, Kathy Charmaz (2008) notes that social phenomenon occur "under pre-existing structural conditions, arise in emergent situations, and are influenced by researchers' perspectives, privileges, positions, interactions and geographical locations" (p. 130). Charmaz has become a leading theorist and advocate for constructivist grounded theory. She argues that grounded theory methods can create interpretive understanding, they need not be prescriptive, and they can escape their positivist roots (Charmaz, 2000).

Constructivism assumes "a relativist ontology, a subjectivist epistemology, and a

naturalistic set of methodological procedures" (Denzin & Lincoln, 2008, p. 14). As a paradigm,

it is highly critical of the main premises of positivistic research. Barbara Israel captures the spirit

of this perspective in her succinct description of constructivism:

> There exist multiple, socially constructed realities that are
> influenced by social, cultural and historical contexts; the inquirer
> and participant are connected in such a way that the findings are
> inseparable from their relationship; and the methods used
> emphasize a continual dialectic of iteration, analysis, assessment,
> reiteration and re-analysis (Israel et al., 1998, p. 178).

Within constructivism, realities are often derived from community consensus regarding "what is

real, what is useful and what has meaning" (Guba & Lincoln, 2005, p. 197). In contrast to post

positivism, this paradigm relies predominantly on qualitative methods and inductive data

analysis (Lincoln & Guba, 1985).

Theory development is of great interest to constructivists and the paradigm is especially

compatible with grounded theory methods (Gibbs, 2001; Lincoln & Guba, 1985). Within

constructivism, theory development is frequently aimed at helping practitioners understand

social problems and relevant interventions (Reamer, 1993). This paradigm recognizes that social

and political contexts strongly influence people and their problems and assumes that all inquiry

is value bound (Gibbs, 2001; Guba & Lincoln, 2005). Indeed, values are seen as central to

research and knowledge production is frequently considered " local and specific" (Guba &

Lincoln, 2005, p. 195).

Constructivist grounded theory consists of flexible strategies rather than formulaic

procedures and thus it allows for a broader diversity of theoretical starting points including

feminist theory, Marxism, and post structuralism (Charmaz, 2006). Constructivist grounded

theorists maintain the flexibility to adopt which coding and analytical techniques suit their data. Accordingly, theoretical sampling, constant comparison, and various coding techniques continue to figure prominently in a constructivist grounded theory study.

The main difference from traditional grounded theory originates within the epistemology and ontology of the constructivist approach. Constructivist grounded theory does not assume the existence of "a uni-dimensional external reality" (Charmaz, 2000, p. 522). As in social constructivism, this methodology acknowledges multiple realities and views the analysis as only one interpretation. Findings are not regarded as generalizable; rather they are seen as conditional statements that may be useful to future researchers as sensitizing concepts. The researcher is acknowledged as a participant in the process; one who co-creates knowledge with individuals and communities (Clarke, 2003). In short, constructivist grounded theory "assumes the relativism of multiple social realities, recognizes the mutual creation of knowledge by the viewer and the viewed, and aims toward interpretive understandings of subjects' meanings" (Charmaz, 2000, p. 510).

An important characteristic of constructivist grounded theory is its theoretical reflexivity. A commitment to symbolic interactionism is not implied in the use of constructivist grounded theory. This provides researchers with the flexibility to work within a framework that fits with their professional values. Grounded theorists are thus free to adopt alternative epistemologies and to combine grounded theory with other approaches to research. For those working within a social justice framework this presents valuable opportunities to combine constructivist grounded theory with participatory action research and critical inquiry (MacDonald, 2001). Many social theories were developed within a positivist scientific framework leading to acceptance of their a priori assumptions (Dey, 1999). Constructivist grounded theory offers progressive researchers a

unique occasion to contribute empirically and inductively to social theory. Thus grounded theorists now have the ability to redefine and construct critical concepts and ground them in the lived experiences of participants (Charmaz, 2006).

This reflexivity permits a fuller exploration of social structure within constructivist grounded theory methodology. Unlike traditional methods, a contextualized grounded theory can address such concepts as power, conflict, and social structure. Constructivist grounded theory assumes that structural properties can have effects independent of the interpretation placed on them (Layder, 1989). Thus, constructivist grounded theorists may utilize situational maps to define how participants construct and enact power and inequality (Clarke, 2003). These tools provide innovative ways in which to depict the complex manner in which social structure and human agency exist interdependently (MacDonald, 2001).

This dissertation draws upon constructivist grounded theory; accepting its fundamental assumptions including a relativist epistemology, reflexive stance toward participants, and flexible approach to constant comparison, coding, and theoretical sampling that contribute to the iterative and emergent nature of the methodology (Charmaz, 2000, 2008; Teram et al., 2005).

3.2.4 Rationale for the Integration of Community-Based Research and Grounded Theory

Community-based research is commensurate with constructivist grounded theory in several important ways. Both methods share a corresponding concern with action and problem solving (Charmaz, 2006). Proceeding from researchers, community members, and participants' commitment to change; the combined approaches offer explanation, understanding and usefulness (Charmaz, 2005; Clarke, 2003). Because community-based research and grounded theory share these commonalities, these methodologies have been used previously to explore labour force participation for people living with HIV.

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For example, general grounded theory methods were used to develop a model of return to work for people living with HIV that focused on the psychosocial factors that affected the decision making process (Ferrier & Lavis, 2003) and in exploring the identity issues of people living with HIV contemplating a return to work (Nixon & Renwick, 2003). Building upon these studies, several researchers utilized evolved methods of grounded theory to explore the impact that HIV has on the employment considerations of people living with HIV as well as the experiences of people living with HIV involved in vocational rehabilitation programs (Conyers, 2004a, 2004b; Maguire et al., 2008). These efforts have contributed valuable concepts and substantive theory towards the broader goal of conceptualizing labour force participation for people living with HIV; results that have been put to good use by service providers and advocacy groups in developing programming and influencing public policy (Canadian HIV/AIDS Legal Network, 2005; Popiel, 2007; Proctor, 2002; Weir, Crook, & Vanditelli - Chapman, 2003).

While the level of community engagement sometimes varies, there is a strong tradition of participatory research in the HIV and employment literature. The existence of numerous community-based research studies contributed towards a shift in the understanding of labour force participation for people living with HIV and a convergence of research methods and approaches. A seminal piece of research conducted on HIV and labour force participation was participatory in nature. Brooks and Klosinski (1999) collaborated with AIDS Project Los Angeles to develop an understanding of the concerns and needs of people living with HIV who were interested in returning to work. The findings contributed to a series of action steps for AIDS service organizations and to the establishment of community programs that provided vocational assessment, benefits counselling, and employment services. Kielhofner et al. (2004) worked with the Employment Options program in Chicago to develop and evaluate community

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vocational services for people living with HIV. Participatory action research strategies were used to improve the program as it developed. This study supported the use of community-based research in achieving sustainable and successful vocational outcomes for people living with HIV (Kielhofner et al., 2004). In a similar article, Paul-Ward et al. (2005) described how community-based research contributed to the development and implementation of employment services for people living with HIV. The authors concluded that despite challenges, the collaborative nature of the program design was responsible for the program's ability to respond to the changing needs of clients and that the research approach was successful in contributing to capacity building of clients, as well as the community partners (Paul-Ward, Braveman, et al., 2005). More recently, Worthington et al. (2012) utilized community-based research methods to develop a conceptual framework of labour force participation for people living with HIV in Canada. The framework was translated into a range of products for use by community organizations including booklets, fact sheets and policy tools.

The increased involvement of people living with HIV, AIDS service organizations, and community groups in HIV and employment research has led to a fuller and more detailed theory of labour force participation. As a result social, community, and structural factors have been better integrated as part of the conceptualization of the issue and resultant knowledge has been grounded in the experiences of people living with HIV. Additionally this research has supported the establishment and evaluation of several community-based vocational programs for people living with HIV in Canada and the United States (Husbands, 2003; Kielhofner et al., 2004; Paul-Ward, Braveman, et al., 2005; Razzano & Hamilton, 2008).

Although often problematized, increased collaboration between researchers, people living with HIV, AIDS service organizations, and community groups has led to capacity building

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within the AIDS sector for individuals and organizations (Flicker et al., 2008). This is evident in the work of community groups such as the Canadian Working Group on HIV and Rehabilitation and the American National Working Positive Coalition, both of whom engage people living with HIV, service providers, educators, and researchers in efforts to establish HIV/AIDS specific, vocational supports. Despite these partnership and program successes, there is still a critical lack of sustainable employment programs for people living with HIV, and recent studies have indicated that despite its rhetoric, community-based research faces many obstacles in genuinely engaging people living with HIV from vulnerable and marginalized populations (Travers et al., 2008). Facing these challenges will be important as collaborative research teams move forward with developing integration in the HIV and employment theory.

The advantages of combining grounded theory and community-based research have been discussed in the methodological literature and many research studies have successfully incorporated both methods (Poonamallee, 2009; Teram et al., 2005). Although less evident, some authors have combined community-based research and grounded theory in conceptualizing labour force participation for people living with HIV. This dissertation builds on the strengths of both methodologies by combining community-based research principles with constructivist grounded theory methods. The advantages of doing so are numerous. Community-based research approaches provide guidance to the research effort and a relevant philosophical and ethical framework in which to engage equitably with community stakeholders. Constructivist grounded theory offers a set of systematic, qualitative methods including constant comparison, coding, and theoretical sampling. The result is relevant community engaged knowledge and employment theory that responds to community needs and is generated by and with the lived experiences of people living with HIV.

3.3 Research Design

Community advisory committees are a common feature of community-based research in the AIDS sector, and have been successful as mechanisms for meaningfully engaging a variety of community stakeholders in the research process. This dissertation research was informed at all stages by a community advisory committee that included people living with HIV/AIDS, service providers, and community members (for a list of members see Appendix A). Five committee members were recruited based on their involvement in the AIDS community and their expertise in HIV and labour force participation. Partnerships with CWGHR, the AIDS Committee of Toronto, Employment Action, and the AIDS Calgary Awareness Association (now known as HIV Community Link) were critical in informing the overall implementation of the research and recruiting participants. Specifically, members of the advisory committee contributed expertise towards refining the research design, nominating potential participants, checking the findings, and participating in community knowledge translation and dissemination. Their role consisted of providing overall guidance, expertise, and support to the student researcher. They were not directly involved in conducting the research or in the data analysis (as is sometimes the case in participatory research). They met with the researcher approximately twice a year (via teleconference) and were individually consulted on an as needed basis.

3.3.1 Sampling Strategy, Data Collection, and Initial Data Analysis

The research employed theoretical sampling, a purposeful sampling strategy which is a defining property of grounded theory (Bryant & Charmaz, 2007). Embedded within the constant comparative process, theoretical sampling directs the researcher to recruit participants and/or texts that are best able to contribute to theory development (Glaser & Strauss, 1967). Theoretical sampling strategies allow for repeated returns to the field to recruit diverse participants whose

perspectives can contribute to emerging categories. Grounded theorists typically continue to recruit participants until they reach saturation, whereby no new information or categories are identified and when, "fresh data no longer sparks new theoretical insights" (Charmaz, 2006, p. 113; Creswell, 1998).

In order to recruit a diverse sample of people living with HIV currently active in the labour force from several regions in Canada; recruitment, data collection, and data analysis were conducted concurrently over three phases. For the purposes of clarity, each phase is discussed separately and includes details relating to the sampling strategy, data collection and early data analysis. It is important to note, however, that consistent with grounded theory methodology, these processes were conducted in an iterative and integrated manner such that ongoing data analysis could inform the sampling approach and revisions/improvements to data collection strategies and the interview guide.

3.3.1.1 Phase I

Prior to the sampling process, ethics approval was obtained from the Conjoint Faculties Research Ethics Board (CFREB) at the University of Calgary (certificate number 6773). Passive recruitment commenced in April 2011 and included posters, blogs, and email blasts distributed within AIDS service organizations and among their community networks. Recruitment partners included AIDS Calgary Awareness Association, The AIDS Committee of Toronto - Employment Action Program, CWGHR, and The Ontario HIV Treatment Network. Study participants were required to meet three main criteria: they had to have been engaged in employment for a minimum of three months, be an adult (18 year of age or older) at the time of the study, and be a person living with HIV. Participants were required to sign the research consent form to indicate that they understood the study, the potential risks and benefits, and that they agree to participate

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in the study (for the research consent form see Appendix B). Phase I recruitment was most successful in Ontario where twenty-six people living with HIV met the study criteria and indicated their interest in participating in the research. Following initial contact by participants with the researcher, interviews were scheduled.

Interviews were conducted in Toronto, Ontario in May, 2011. Twenty, in-depth, face-to-face, semi-structured interviews were conducted by the researcher in private offices provided by The AIDS Committee of Toronto and CWGHR (six participants failed to show for the interview). The majority of the interviews lasted between 45 minutes to1 hour in length (see appendix C for the interview guide). Participants were asked a range of questions about their motivation to work, employment experiences, challenges related to labour force participation and experiences with vocational supports. Interviews were audio taped and field notes taken for later transcription and analysis. Following each interview, participants were provided with a twenty five dollar honorarium. Selected audio tapes were checked, and reviewed between interviews in order to inform ongoing data collection. Initial review confirmed success in recruiting a diverse sample of people living with HIV including women, gay men, trans identified participants, people from varying racial and ethnic communities, immigrants, and those with a history of addiction issues (further details on participant characteristics are provided in Chapter 4).

All electronic data including computer files and digital audio files were password protected and secured on the researcher's home computer and on a secure, online, back-up server. Hand written notes, printed transcripts and paper codes were secured and locked in the researcher's home office.

Audiotapes were transcribed and the data were analyzed using grounded theory coding methods. Four interviews were transcribed by the researcher, following which a transcriptionist

was hired to complete all of the remaining interviews. Initial, line-by-line, paper coding was

conducted on some of the data to identify initial codes and properties related to the phenomenon

of labour force participation. In grounded theory, conceptual codes capture patterns and themes

in the data, indicate a relationship between data and theory, and organize them under a title

(Bryant & Charmaz, 2007). This initial phase of coding involved naming each line or segment of

the data in order to identify ideas on which to build the analysis (Charmaz, 2006). Memos were

used to document initial ideas, to develop insights regarding emerging concepts, and to inform

ongoing data collection.

3.3.1.2 Phase II

　　While transcription and analysis continued on the initial data, six additional participants

subsequently indicated an interest in participating in the study. Throughout the month of June

2011, four additional interviews were conducted (two participants did not attend interviews).

Two face to face interviews were conducted in Toronto, Ontario; one face to face interview was

conducted in Calgary, Alberta; and a telephone interview was completed with a participant in

Ottawa, Ontario. Similar methods used in the earlier interviews were followed for the phase II

interviews; however, some slight changes in prompts were incorporated based on participant

responses and emerging data analysis. Specifically, in interviews the researcher actively

prompted for perceptions of and experience with public policy and income supports; data that

were less prevalent in earlier interviews. While conducting these interviews the researcher

continued to check, question, and interpret the data and to compare it to ongoing coding efforts.

　　Upon completion of the additional interviews and transcription of all the audio tapes, the

researcher continued to complete the line by line coding process until data from all 24 interviews

had been coded on paper. The coding process entails breaking down, or fracturing the data into

units that represent particular incidents and then assigning them conceptual labels with the central question in mind: what is it that we can learn from people who have successfully navigated through employment while also living with HIV? (Glaser, 1978). Care was taken to move through this initial coding process quickly without over thinking each code but also noting when certain codes appeared to hold conceptual weight (Charmaz, 2006). During this process the researcher remained open to all possible theoretical directions indicated by the data. Methodological and conceptual memos were completed documenting ideas, issues, questions, concepts, and both strengths and gaps in the data (Lempert, 2007).

Given the researcher's familiarity with the research literature in this area, conscious effort was focused on preventing the imposition of preconceived notions on the data. This process involved actively bracketing earlier research work and coding for processes or actions rather than established theoretical categories (Charmaz, 2006). Additionally, the researcher diagrammed throughout this process in order to capture the connections between codes and the complexity associated with the phenomenon. Completion of the line by line coding process resulted in a diverse and complex set of initial, provisional codes rooted in the data. As per grounded theory's focus on the constant comparison process, initial coding identified some clear conceptual areas to be further explored during a more focused round of coding.

A second round of coding commenced in January of 2012. Two hundred and forty three significant and frequent earlier codes were entered into NVIVO computer software along with associated text from the transcripts. The software was then used to synthesize, integrate, and organize the data. During this process the researcher compared, analyzed and generated codes and sub codes that could best handle emerging data. Where possible, the researcher initiated a process of conceptual ordering, whereby the data was organized into provisional categories

according to their properties. Additionally, this round assisted the researcher to compare data with data and to identify gaps in the research findings that could be addressed in supplemental data collection. Brief consultation meetings were scheduled with the doctoral supervisor in November 2011, February 2012, March 2012, and June 2012. In the latter meetings coding progress was reviewed and early ideas regarding analysis were discussed and documented.

3.3.1.3 Phase III

In grounded theory, theoretical sampling follows conceptual development. A third round of sampling was conducted to recruit additional participants whose perspectives could contribute to emerging, provisional categories and address identified gaps in the data. Rationale for an additional return to the field included a need to explore policy structures in a different Canadian jurisdiction, a desire to speak with individuals who had participated in other forms of vocational programming, and a need to confirm theoretical saturation of prominent themes. Working within CWGHR's national network of community service providers, an additional sampling strategy was planned and implemented in Vancouver, B.C. Passive recruitment strategies similar to those used in Ontario and Alberta were successful in identifying nine participants meeting study criteria and indicating an interest in participating in the research.

Face to face interviews were conducted in Vancouver with eight participants (one participant did not attend the interview). Interview methods were similar to those used in earlier phases, with the only variation being some additional prompts used when necessary as part of the interview dialogue. Specifically, participants were prompted with additional queries about income support policies and access to medication in B.C. Audio tapes from seven of the Vancouver interviews were transcribed, integrated with the existing data, and analyzed using methods similar to earlier phases. Failure of the audio equipment on one occasion meant that

data from one interview could not be utilized in the study. A line by line approach was also used with the Vancouver transcripts, however, coding became more selective as categories or conceptual elements of a theory began to emerge in the previous interviews (Glaser & Strauss, 1967). Analysis conducted on these data confirmed that theoretical saturation had been reached for some earlier themes; meaning that successive interviews revealed no new properties nor any further insight into the emerging theory (Bryant & Charmaz, 2007). Also additional content related to public policy and jurisdiction enriched the data set.

3.3.2 Data Analysis: Theoretical Coding

Theoretical coding is the process of conceptualizing how identified codes may relate to each other and be integrated into theory (Glaser, 1978). NVIVO software was again utilized to conduct a final round of theoretical coding in order to finalize categories and their properties and to conceptualize the emerging theory (Glaser & Strauss, 1967). In this process, frequent earlier codes were used to sort through the data and make decisions about which codes were most relevant for categorization (Charmaz, 2006). From this process, categories and properties related to the phenomenon of labour force participation were identified and related back to the central phenomenon of working successfully. This level of analysis also involved axial coding, the process of relating categories to their subcategories (Strauss & Corbin, 1998). This stage involved asking questions about the relationships among categories and ensuring that these relationships are supported in the data.

All ideas related to data analysis were memoed within NVIVO (linked to codes and categories where applicable) throughout the coding, transcribing and writing process. Memo writing assisted in documenting initial ideas and developing insights regarding emerging theory. Developed categories were charted using an excel spreadsheet and relationships between the

categories were captured in a basic diagram. These materials were reviewed with the advisory

committee (in order to ensure relevance) and the supervisory committee (in order to report

progress and obtain feedback) towards the end of the coding process.

3.4 Ethical Considerations

This study did not pose more than a minimal risk to participants. Nevertheless, several

procedures to protect participants and to ensure their confidentiality were enacted. The research

protocol was submitted to the University of Calgary Conjoint Faculties Research Ethics Board

for approval prior to any contact with research participants. Additional amendments were sought

and obtained from the CFEB where changes to the original submission warranted, notably to

integrate feedback on sampling from community partners, to accommodate telephone interviews,

to allow for transcription by a third party, and to allow for recruitment in Vancouver, B.C..

Prior to each interview, the research consent form was thoroughly reviewed with each

participant and his or her rights as a voluntary research participant were discussed. Participants

were informed of all study procedures, the time commitments required for participating in the

interview, as well as their right to withdraw at any time. All participants signed the research

consent form prior to commencing the interview. In the case of the telephone interview, the

research consent form was forwarded to the participant via email prior to the scheduled interview

date. The consent form was signed, scanned, and a copy returned via email prior to

commencement of the interview.

In order to ensure confidentiality, no information identifying the participant was recorded

on the written transcripts or any computer files. In tracking participant information, numeric

codes were assigned to match digital audio files, transcripts, and memos with participants. All

electronic data including computer files and digital audio files were password protected and

secured on the researcher's home computer and on a secure, online, back-up server. Hand written notes, printed transcripts, and paper codes were secured and locked in the researcher's home office. Quotations in the dissertation or any reports or publications arising from the dissertation will be anonymized. Following completion of the study data will be stored in a locked location at Mount Royal University, accessible only to the researcher and the doctoral supervisor. Digital audio files will be destroyed following completion of the doctoral dissertation.

3.5 Trustworthiness

There are five potential outcomes by which a constructivist study can be assessed for trustworthiness and authenticity: fairness, ontological authenticity, educative authenticity, catalytic authenticity, and tactical authenticity (Guba & Lincoln, 2005). Charmaz (2005) expands on this in offering criteria on which grounded theory and social justice inquiry can be judged. These criteria include credibility, originality, resonance, and usefulness (Charmaz, 2005). Each of these categories address important questions related to empirical study and development of theory. Consideration for the above factors has been an essential component of the research design, and was achieved primarily through a deep and reflexive engagement with people living with HIV and allied communities. Adoption of a community-based research framework helped to ensure that the research remains original, authentic, useful, and contributes to community identified priorities for social change.

Important methodological considerations of this approach included employing a community advisory committee and member checks to ensure that the data stand as adequate and sufficient. Involving the community advisory committee in an ongoing process of evaluation and reflection helped to ensure that the analysis provides a relevant conceptual rendering of the data, portrays the fullness of the experience, offers deep insights, and offers interpretations that

can be used in practice (Charmaz, 2005). The results of the data analysis were shared with the advisory committee through teleconference meetings and on an ad hoc basis in order to engage their experience and insight in interpreting the data. This form of member checking or taking ideas back to the community for confirmation was conducted to elaborate upon categories and ensure that they portray the fullness of the studied experience (Charmaz, 2006). During this process, major categories were explained to advisory committee members in order to assess the degree to which these categories resonated.   This process involved identifying overlooked data or engaging in discussion of the properties of certain categories and the possible identification of new categories (Charmaz, 2006). These processes helped to ensure that the research findings are both trustworthy and authentic and that they resonate in the community.

CHAPTER FOUR: INTRODUCTION TO THE RESEARCH FINDINGS

4.1 Introduction

The purpose of this study was to develop a conceptual framework identifying the factors that shape and influence the successful labour force participation of people living with HIV in Canada. A community-based research framework and grounded theory methods were selected as most appropriate for completing this project of inquiry. As described in Chapter Three, systematic processes using a grounded theory approach were employed to gather and analyze qualitative data from 31 research participants. The results consist of a conceptual framework that describes and explains the key concepts shaping participants' experiences of working successfully. Chapters Five through Eight outline detailed findings of the dissertation research. This chapter serves as an introduction to the research findings, including a summary of the participants' demographic factors, brief composite profiles of three research participants, and an overview of the conceptual framework arising from the findings.

4.2 Summary of Participant Demographics

As indicated earlier, HIV research is a complex endeavour further complicated by the diversity of populations affected by the disease and a variety of contextual and social structural factors. Reflecting this complexity, much of the HIV and employment research has been conducted using samples that fail to fully reflect the diversity in the field. As discussed in Chapter Three, the use of theoretical sampling provides grounded theorists with the opportunity to continue recruitment until evolving concepts have been adequately saturated with rich description (Charmaz, 2006). In the current study, theoretical sampling was utilized primarily to

ensure saturation was achieved while also ensuring that a diverse sample was included, and one that broadly reflects existing HIV prevalence in Canada.

Personal and demographic factors can play an important role in successful labour force participation for people living with HIV (Worthington, O'Brien, et al., 2012). This section will provide a brief profile of the research participants by reviewing demographic factors that are relevant to HIV and employment: gender identity, age, length of time since HIV diagnosis, ethnicity and immigration status, marital and family status, and vocational factors. A total of 31 successfully employed adults living with HIV voluntarily participated in the study. As part of the interview, participants responded to a range of open-ended questions regarding their personal and demographic characteristics. Thus, the findings from these questions relied on participant self-identification. Participant demographics are summarized in Table 4.1.

4.2.1 Age and Length of Time since HIV Diagnosis

Study participants ranged between 28 and 62 years of age, with the majority being between the ages of 40 and 55 years. The average age was 44 years. The length of time since HIV diagnosis can impact the employment trajectories of people living with HIV and may play a determining factor in whether or not participants have experienced episodes of illness (Dray-Spira et al., 2006). Accordingly, participants were queried about the length of time since their HIV diagnosis. In all, eight participants reported being relatively recently diagnosed, having received their HIV diagnosis after 2008. Twelve participants reported receiving an HIV diagnosis between the years 2000 and 2007. An additional 11 individuals were diagnosed with HIV prior to 1999. Six of these participants were diagnosed before the advent of antiretroviral therapy in 1996, a critical turning point in the life expectancy and disease trajectory of the North American epidemic. Many participants spoke in detail about the impact their diagnosis has had

on their personal and work life and these narratives will be discussed further in following sections.

4.2.2 Gender Identity, Ethnicity and Education

Vocational obstacles related to gender can impact an individual's employment outcomes and the research literature has indicated that these may be especially important in an HIV context (Burns, Young, & Maniss, 2006; Solomon & Wilkins, 2008). With respect to gender identity and sexuality, 23 study participants identified themselves as gay men, accounting for close to 75 percent of the total sample. Additionally, five participants were heterosexual women, two were heterosexual men, and one participant was transgendered.

Those interviewed for this inquiry came from diverse ethnic backgrounds, including twenty Caucasian participants, four participants from Black/African/Caribbean communities, three Latin Americans, two Aboriginal persons, one South Asian participant, and one individual of mixed descent. Twelve of the participants had immigrated to Canada from a variety of regions including Latin America, Europe, Israel, Africa and the Caribbean. In general, research participants were highly educated. Twenty participants indicated having attended or completed at least one University degree and nine reported receiving some College education. Two participants had completed high school education.

4.2.3 Household and Family Status

Social support and a stable partnership is cited in the HIV and employment literature as an important facilitator of labour force participation for those living with HIV (Jia et al., 2004). With respect to household and family status, the majority (22) of the research participants reported being single and living alone. Five individuals identified belonging to a same sex

relationship (male) and cohabitating with their partner. Of the five female participants, three were sole support parents and one was married with children.

4.2.4 Vocational Factors

As part of the selection criteria all participants had been successfully engaged in the labour force for a period of three months or more at the time of the interview. Eighteen participants were currently engaged in full time work (37.5 hrs a week or more), and 13 were working part time (less than 37.5 hrs a week). Three individuals were working on a casual or on-call basis (varied hours) and two were in contract positions. With respect to length of time employed at their current job, five participants reported being there for less than 1 year. The majority of participants (17) had been employed at their current job for a period of 1to 5 years. Five participants indicated that they had been with their current employment for six to 10 years and four individuals reported having been employed at their current job for 11 or more years.

Study participants reported a range of occupations: 13 were working in health and social services, four in the business sector, four in hospitality, three in education, three in financial services, two were general labourers, one was in the transportation sector, and one person was in government services. The majority (20) of participants reported receiving some form of vocational services in the past, while eleven did not receive any formal vocational supports.

Table 4.1 Participant Demographics

Age	Gender	Ethnicity	Residency /Place of Birth	Education	Hours of Work	Yrs in Job	Employment Sector
58	Gay male	Caucasian	Born in Canada Ontario	College	Full time	30	Government
33	Gay male	Caucasian	Born in Canada Ontario	University	Part time	12	Business
31	Gay male	Caucasian	Born in Canada Ontario	University	Part time	.25	Transportation
39	Female	Black, African, Caribbean	Immigrated Ontario	High School	Part time	.75	General Labour
43	Female	Aboriginal	Born in Canada Ontario	University	Full time	5	Financial services
39	Female	Black, African, Caribbean	Immigrated Ontario	University	Full time	2	Health and Social Services
51	Straight male	Caucasian	Born in Canada Ontario	University	Part time Contract	4	Health and Social Services
52	Gay male	Caucasian	Born in Canada Ontario	High school	Full time	8	Financial services
48	Gay male	Caucasian	Born in Canada Ontario	College	Part time	1	Health and Social Services
44	Female	Black, African, Caribbean	Immigrated Ontario	College	Part time	2	Health and Social Services
38	Gay male	Mixed ancestry	Born in Canada Ontario	University	Part time Casual, on call	.25	Health and Social Services
55	Gay male	Latin American	Immigrated Ontario	University	Part time Casual, on call	10	Hospitality

57	Gay male	Caucasian	Born in Canada Ontario	University	Part time Casual, on call	20	Education
38	Gay male	Caucasian	Born in Canada Ontario	University	Full time work	3.5	Financial services
56	Straight male	Latin American	Immigrated Ontario	College	Full time work	2	General Labour
29	Gay male	South Asian	Born in Canada Ontario	University	Full time work	2	Hospitality
45	Gay male	Caucasian	Born in Canada Ontario	University	Part time	2	Health and Social Services
32	Transgendered	Aboriginal	Born In Canada Ontario	University	Part time	2	Health and Social Services
44	Gay male	Black, African, Caribbean	Immigrated Ontario	College	Full time	1.5	Health and Social Services
46	Gay male	Caucasian	Immigrated Ontario	College	Full time	.9	Business
39	Gay male	Latin American	Immigrated Ontario	University	Full time	2	Health and Social Services
47	Gay male	Caucasian	Born in Canada Ontario	College	Full time	1.25	Health and Social Services
50	Gay male	Caucasian	Immigrated Alberta	University	Full time	5	Business
57	Female	Caucasian	Born in Canada Ontario	University	Part time	8	Business
50	Gay male	Caucasian	Born in Canada British Columbia	University	Full time	5	Health and Social Services
43	Gay male	Caucasian	Immigrated	University	Full time	5	Hospitality
28	Gay male	Caucasian	Immigrated	University	Part	4	Education

			British Columbia		time		
46	Gay male	Caucasian	Born in Canada British Columbia	University	Full time	5	Health and Social Services
43	Gay male	Caucasian	Immigrated British Columbia	College	Full time	9	Hospitality
62	Gay male	Caucasian	Born in Canada British Columbia	College	Full time Contract	8	Education
43	Gay male	Caucasian	Born in Canada British Columbia	University	Full time	7	Health and Social Services

4.3 Participant Composite Profiles

One limitation of grounded theory is the tendency to fracture the data as part of the constant comparative process. While this process is imperative for generating a thorough grounded theory, the voices of participants can frequently become lost in the process. This drawback can be exacerbated by the use of qualitative data analysis software (such as NVIVO) which requires that participant transcripts be cut up and assigned to emerging categories. Throughout the coding process I struggled with this aspect of grounded theory analysis, at times feeling like I was literally carving up and filing participants' narratives. While not unexpected, given the nature of the research, many participants revealed intimate details from their lives and discussed many emotionally difficult experiences. Having spent many months meeting the research participants and listening intently to their employment experiences, it felt somewhat unsettling to lose a complete sense of their stories through the coding process. In order to best honor and respect participants' stories, I created the following composite profiles. Composites were chosen in order to incorporate diversity of experience and to provide the reader with several

typical experiences but at the same time to protect the confidentiality of research participants.
They are presented here as a companion to the conceptual and theoretical material to follow and
as a medium through which diverse participant realities may be more fully understood.

4.3.1 Frances

Frances is divorced and lives at home in Alberta with her two teenage sons. In 2009,
while working on contract she become extremely ill and was diagnosed with HIV. She has been
working full time in an administrative position for the last eight years providing client services.
She has worked in the industry for over twenty years and was relatively healthy for much of that
time except for two minor surgeries which required brief absences from work. Following her
diagnosis, Frances was off work for a long period of time due to pain, debilitating illness, and the
emotional impact of her HIV diagnosis. As she was a contract employee, she did not receive any
benefits and had to rely first on unemployment insurance and then on provincial public income
benefits as her only source of income. During this time her two teenage sons helped care for her
and she received supplemental support from women in the Black/African/Caribbean community.
With time she was able to return to full time work.

Upon her return to work she did not tell her co-workers or her managers the reason for
her lengthy absence, instead telling them she had contacted a serious viral illness. Due to the
stigma surrounding HIV, she is terrified that her status will be found out and that her co-workers
will gossip about her. In the past she has witnessed her co-workers saying derogatory things in
regards to HIV and she feels certain that her workplace would be a stigmatizing environment if
she disclosed her status. Despite enjoying the company of some of her colleagues, she generally
keeps her distance from her co-workers and avoids any work related social situations.

As a sole support mother, Frances feels that she has no choice but to remain in her current position. Due to a lengthy episode of illness with no benefits she owes a lot of money to different creditors and feels overwhelmed at trying to pay off her debts. She works in order to provide the basics for herself and her children. Due to the booming Alberta economy, she has now gained permanent status at work, and she receives good benefits including three weeks of holidays, sick leave, and a flexible schedule. Although she is just getting by financially, her job gives her peace of mind as she knows that her healthcare and medication needs will be covered through her benefits plan at work. She has access to basic long term disability coverage but does not contribute any more than the basic amount as she is worried that they will ask questions about her health and she doesn't want to compromise her status.

Frances likes the outlet she gets from work and says that if she had to stay home every day she would go crazy. She likes to be out in the world and enjoys interacting with other people. In her spare time she volunteers with a community AIDS organization.

Frances reports suffering from poor health and feeling down at times. When this happens she takes to her bed and sleeps in order to get herself feeling better. While she is successfully maintaining her current job, her diagnosis has suspended many of her hopes for the future and she is taking things one day at a time. She would love to move up within the hierarchy at work some day; however, currently she does not feel as though she could handle a promotion to a better position and she is not feeling able to take on more responsibility at work. Lately, she has been struggling to meet the performance expectations of her current position and this has been noted in supervision. She is doing her best to improve her performance and stay healthy.

Frances struggles with depression. She credits her religious faith for getting her through her darkest periods. She reports that sometimes she has trouble concentrating on her work and

feels so down that she has to leave her desk and find a private place to cry. Sometimes it is very difficult to get up and go to work in the morning and she has to force herself to stick with this routine. Some nights she sleeps up to 12 hours so that she will have the energy for work the next day. She relies on her children, her close circle of friends, and her religion for emotional support.

Currently she is not taking any medication for her HIV, although her doctor has indicated that it may soon be time to start combination therapy. To Frances, this is a terrifying proposition. She is worried about the possible side effects of the medication and whether she will have difficulties adjusting to the meds. She has heard some terrifying stories from friends that have been through this experience and she is worried that she will not be able to work. She has saved up her vacation time in case she needs to take time off during this period. In order to prepare she has researched common medications and the side effects so that she can have an informed discussion with her doctor and advocate for medication that will be as easy to tolerate as possible. She has prescription coverage at work; however, she is not sure what percentage of her HIV medications will be covered and how much she will be expected to contribute.

4.3.2 Glenn

Glenn is a 33 year old gay man living in British Columbia who was diagnosed with HIV two years ago. Before doing his current job Glenn managed a restaurant. This was a stressful position that required "crazy hours" and it did not match his career goals. He was responsible for managing several other employees as well as dealing with customers. Upon diagnosis, he disclosed his status to the owner of the restaurant who reacted negatively and told several other co-workers who also had extremely negative reactions. He decided to change careers as he was having trouble managing the stress of the job and found that the hostile environment was

negatively impacting his health. After leaving this job he was determined to find a career option that meant less stress, enabled him to prioritize his health, and that reflected his passion.

Glenn is now working part time in the family business where he helps run the company and provides services to clients. He has disclosed his illness to his family and they are generally supportive although they prefer not to discuss it on a regular basis. Glenn likes this current employment arrangement as he feels fortunate to not have to face any additional workplace stigma or discrimination. Concurrently he is studying business part time at his local college. His goal is to eventually open his own business. Glenn reports that this combination of work and study is working very well for him. Working in his family's business means that he has a lot of flexibility in his schedule, which accommodates his studies well. This has assisted him in finding a balance between working in the store, studying, and time for recreation. Glenn is extroverted and enjoys interacting with people on the job and making new friends. Despite his health issues he generally has a positive attitude towards life and work.

Glenn is combining part time work with provincial disability income benefits. This gives him some flexibility to work while also being guaranteed a minimum income. His monthly hours at work vary; however, in months where his work income exceeds his disability payments, part of the extra income is clawed back by his benefits provider. In addition, his prescription and dental care are covered by his disability provider. This works very well for Glenn as it provides a safety net for times when he cannot work as much. For instance, at one point he was finding that stress was really getting to him and he needed to take a couple of weeks off. Despite not working he was still able to receive his disability income. In general, he is earning several hundred dollars a month more than if he were on disability and not working. This extra income helps him to afford better quality food and a nicer apartment.

The family store is a very small business and they are not able to provide benefits to their employees. Fortunately, Glenn receives his HIV medication free of charge from the local health clinic where he goes for care. He feels secure in this arrangement as he knows that regardless of his employment status he will be able to cover his medication costs. If he were to move to a new position he wouldn't have to worry about whether or not the employer has adequate coverage. At times Glenn finds it a challenge to balance work, school, and life with HIV. He spends a lot of time and effort trying to keep himself organized so as to better handle these demands. Having a lot of flexibility is crucial for Glenn as he is still learning what his body can and cannot handle. At this point in his life he doesn't feel he can work excessive hours and values time away from work where he can spend time alone and focus on self-care.

4.3.3 Ricki

Ricki is a 32 year old Trans identified individual living with HIV. At the time of the research interview Ricki presented as a male and continued to identify this way throughout his engagement in the study. Ricki was diagnosed with HIV and Hepatitis C in 2005 and wasn't able to work at all for several years following his diagnosis due to several health challenges. Ricki lives alone in Ontario and is estranged from his family who don't accept his identity as a Trans person.

Currently, Ricki works 25 hours a week as a peer researcher for a local health and social services agency and has been doing this successfully for approximately seven months. Ricki prefers to work part time as he continues to receive monthly provincial disability income. Combining part time work and disability benefits works well for Ricki. Although the agency doesn't provide benefits, he is paid in cash weekly. He reports that since he has been working he is ahead at least $400.00 per month compared to when he wasn't working. This helps pay for

basics like better food and more clothing. A while ago he considered moving up to full time work, however all his medications are covered through his provincial drug card and he felt nervous about leaving this arrangement for coverage by a new employer. Aside from that he relies on AIDS service organizations periodically to help make ends meet and for services such as food bank and access to medical marijuana.

Before his diagnosis, Ricki lived on the street for several years. When he learned of his status he went for counselling at a street front health and social service agency. He used this support to deal with his addiction, find housing, and stabilize his life. In time, this strong connection with the agency led to employment there. Ricki enjoys his job as a peer researcher where he is able to use his experience living on the street to connect with and recruit people to participate in community research efforts. He likes keeping busy and getting out of the house. At work he has been able to improve his skills and now feels more confident. Helping others and contributing to HIV research are factors that he finds especially rewarding at work.

Ricki is taking medication for both his HIV and hepatitis C. He reports experiencing serious side effects including fatigue and extreme nausea. However he finds that work really helps with the side effects as he feels better when he is moving around. When the side effects are at their worse, he uses marijuana to help manage them. Ricki's employer has been very supportive and he has a trusting relationship with his supervisor and the other staff. They all support each other at work and when they are having personal or health issues. His colleagues at work are aware of his HIV status and they know that at times he uses medical marijuana to deal with his medication side effects. For the most part they have been supportive and non-judgmental and this has made it easier for him to work there. He would like to stay at the agency and work his way into a full time job sometime in the future.

In summary, these composites were developed in order to provide the reader with several typical experiences and to offer a more holistic understanding of the challenges and issues many participants encounter in the labour force. While reflective of the kinds of experiences participants reported they do not capture all of the participant narratives and characteristics. They are presented here as an accompaniment the material to follow and as a medium through which participant realities may be more fully understood.

4.4 Overview of the Theory

This section presents an overview of the conceptual framework that emerged from this study, *A Conceptual Framework of the Processes and Structures that Shape the Successful Labour Force Participation of People Living with HIV in Canada* (see Figure 4.1). This framework contributes to emerging theory guiding vocational program and policy development for people living with HIV in Canada. In the constructivist tradition, theory is simply, "a set of interrelated concepts, definitions, and propositions that present a systematic view of events" (Glanz, Rimer, & Viswanath, 2008, p. 26). Constructivist theory tends to be provisional and embraces multiple perspectives (Charmaz, 2005). Relevant theory can fulfill several important functions including describing and explaining important social phenomenon (Howe, 1987). In less developed fields such as HIV and employment, theory may serve the critical function of specifying the factors influencing the phenomena of interest (Glanz et al., 2008). Additionally, grounded theory can be an extremely valuable tool in social work where best practice is guided by a clear framework of explanation (Howe, 1987). As such, it is extremely important that conceptual frameworks, such as this one, closely fit the data and accurately reflect the realities faced by research participants.

In this study, after working with the data that emerged from the interviews, the data have been conceptualized within an ecological perspective as it was found to be best suited to capture the complexity of the issues being explored. As described in Chapter 2, first conceived by Urie Bronfenbrenner (1979), the ecological perspective is a theory of environmental interconnections and their impact on human growth and development. In ecological models, the social environment is theorized as a set of nested structures which describe the interrelated structures and processes that shape the course of human development. Ecological models are better suited to explaining the complex phenomena frequently encountered in social work practice than are more linear approaches (Gitterman & Germain, 2008). For this study, an ecological perspective provides a framework that captured the intersecting and mutually reinforcing nature of the emerging categories as well as providing for detailed analysis of the data at multiple conceptual levels (intrapersonal, interpersonal, and environmental).

Ecological frameworks emphasize the environmental and policy contexts of behaviour while incorporating social and psychological influences (McLeroy et al., 1988). They can be effective in providing a comprehensive framework for integrating multiple theories and in developing intervention strategies at several levels (Sallis et al., 2008). Four core assumptions characterize ecological theories: 1) behaviour is influenced by social environments and personal attributes; 2) environments are multidimensional and may be actual or perceived constructs; 3) interaction (transactions) occurs at varying levels of analysis; and 4) people simultaneously influence and are influenced by their social environments (Sallis et al., 2008).

An ecological framework is a good theoretical fit with a strengths perspective and a social model of disability as it shares an appreciation for the ability of individuals to respond constructively to their social environments and the capacity to challenge its limitations. Drawing

from deep ecology, each component of ecological models are viewed as interdependent and reciprocal to the other levels (Gitterman & Germain, 2008). Well-accepted within public health disciplines, ecological frameworks have also become prevalent within social work and have been effective at guiding social interventions at a variety of levels (Connolly & Harms, 2012; Gitterman & Germain, 2008; Saleebey, 2001; Ungar, 2002). This study will draw upon Mcleroy, Bibeau, Steckler and Glanz's Ecological Model for Health Promotion (1988) as it closely fits the present data. A variation on Bronfenbrenner's work, this model offers five levels of analysis which can be viewed as influencing behaviour. These are 1) intrapersonal factors, 2) interpersonal factors, 3) institutional factors, 4) community factors and 5) public policy (McLeroy et al., 1988).

Although other theories and frameworks have been used by researchers to conceptualize HIV and employment, an ecological perspective was seen as the best fit for interpreting participants' complex experiences related to living and working with HIV. Three specific reasons establish an ecological perspective as most appropriate for this data. First, it provides a framework through which personal and structural level processes can be considered simultaneously. This is an important factor as environmental structures have not been adequately conceptualized within most vocational rehabilitation literature (Bluestein, 2006). Secondly, it is not a deterministic model, allowing a role for both structure and personal agency, as well as for reciprocity between the two forces. Thirdly, an ecological framework can incorporate a high degree of equifinality, an acknowledgement that similar goals can be met "from different initial conditions and among different pathways" (Connolly & Harms, 2012, p. 60). These are all important factors of any framework addressing HIV and employment.

Despite their widespread acceptance by social work and public health practitioners, ecological models have been critiqued by a variety of authors. For instance, Micheal Ungar (2002) has described how early social ecological models emphasized goodness of fit and assumed that all members of society benefited from an equitable balance of power. He further notes that issues of oppression were not fully addressed in ecological models until more recently. This critique was also discussed by Dennis Saleebey (2001) who viewed contemporary social work ecological models as conservative in nature and protective of the status quo. Within these models, he argues, the primary emphasis was on helping people adapt to oppressive structural conditions rather than to confront institutional barriers. Connolly and Harms (2012) further critique ecological models as failing to provide adequate explanatory power and as lacking in practical application. Nevertheless, more recent ecological models have begun to address these critiques and have attempted to better incorporate critical conceptualizations of structural factors and the role of power. Efforts to address these critiques and to integrate these ideas into the present framework were a guiding principal of this research and a methodological imperative given the nature of the emerging data.

There are six main categories that form this conceptual framework and explain the data as they emerged from the narratives of research participants who were living and working with HIV. At the centre of the framework are two main categories that constitute the psychosocial processes involved in working successfully. These include intrapersonal processes and interpersonal processes. Each of these categories subsumes a number of smaller subcategories; processes that contribute to successful employment. Three key environmental structures shape and influence the overall process of working successfully. These are summarized in the categories: work, community and public policy. Each of these categories in turn contains several

relevant sub-categories. Additionally, within ecological frameworks, cultural factors and environments frequently operate at multiple levels (Sallis et al., 2008). This framework includes one intersecting subcategory related to culture, power, and social beliefs. This category, entitled Stigma and Discrimination is embedded in, surrounds, and influences the processes and structures related to the phenomenon of working successfully. Consequently, it will be described in a series of subcategories embedded, when applicable, within each ecological level.
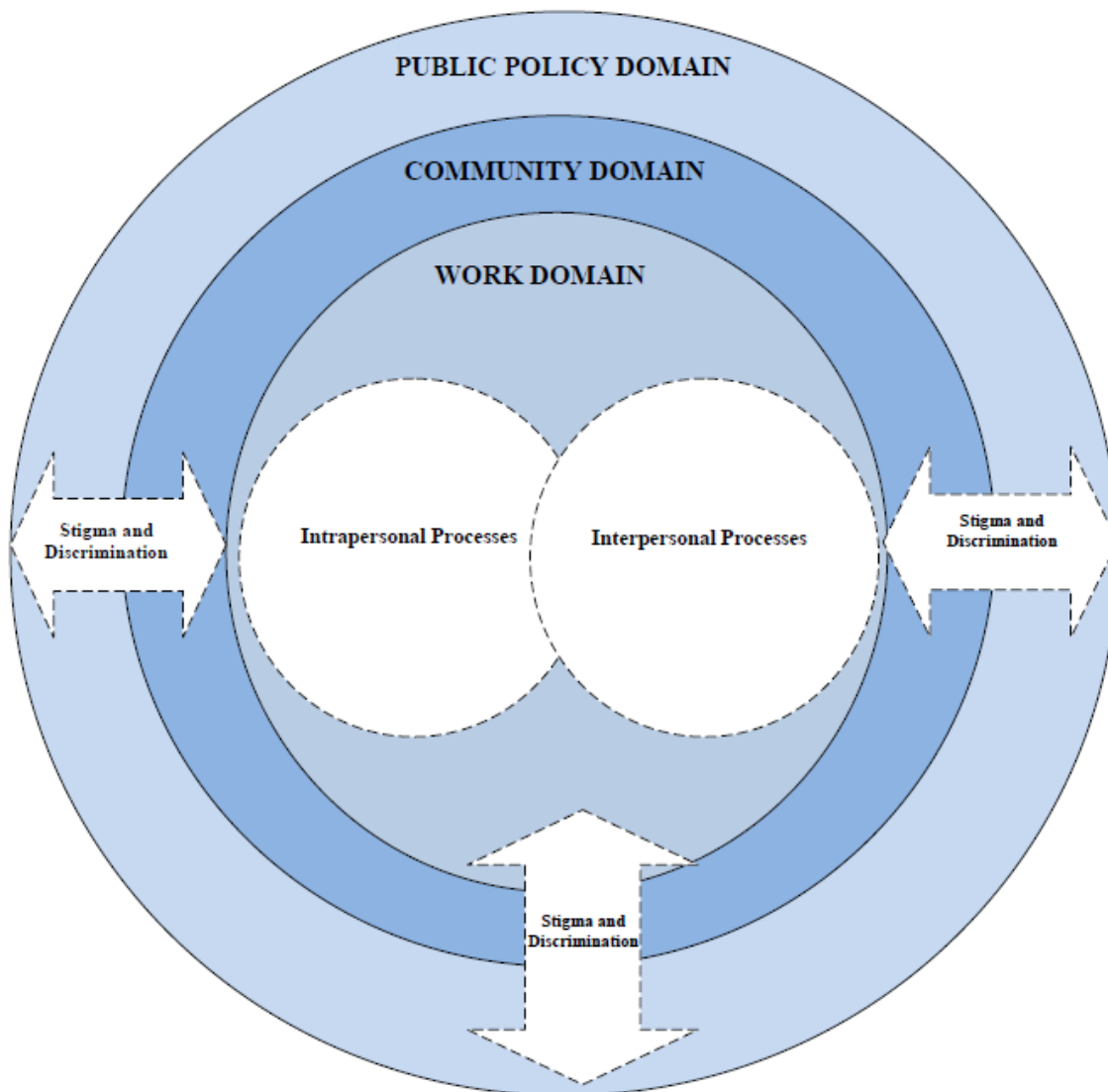
Figure 4.1 Work in Progress: A Conceptual Framework for Understanding the Successful Vocational Experiences of People living with HIV in Canada

4.5 Chapter Summary

In summary, an ecological framework will be used to describe and discuss the

participants' experiences of working and living with HIV. These experiences have been

conceptualized within the following levels of analysis: 1) intrapersonal factors, 2) interpersonal

factors, 3) institutional structures, 4) community structures and 5) public policy. Chapters Five through Eight further describe these key categories, their role in the framework, and their relationship to each other. Excerpts and examples from the data are provided to illustrate the descriptions presented.

CHAPTER FIVE: THE INTRAPERSONAL PROCESSES

5.1 Introduction

Charmaz (2006) recognized the need within grounded theory scholarship to present research findings in ways that acknowledge both evidence and analysis. Accordingly, Chapters Five through Eight will present findings from this grounded theory inquiry in a style that offers both detailed and descriptive understandings of the data. This chapter begins that discussion by identifying and describing the key intrapersonal level processes that form the central elements of the ecological conceptual framework.

As indicated previously, two broad areas of psychosocial process characterize participants' successful experiences in the labour force (see fig. 5.1). These key elements of the conceptual framework are personal level processes that participants most often identified as directly involved in their employment experiences. Consistent with grounded theory methodology, each category within the framework emerged directly from participant narratives. Within this ecological framework, the first category is intrapersonal processes. Additionally, within each of these key categories are a variety of related subcategories. This chapter describes the properties (qualities, attributes, and conceptual characteristics) and dimensions (range or extension) of the intrapersonal processes in detail and includes examples and narratives from research participants (Dey, 1999).
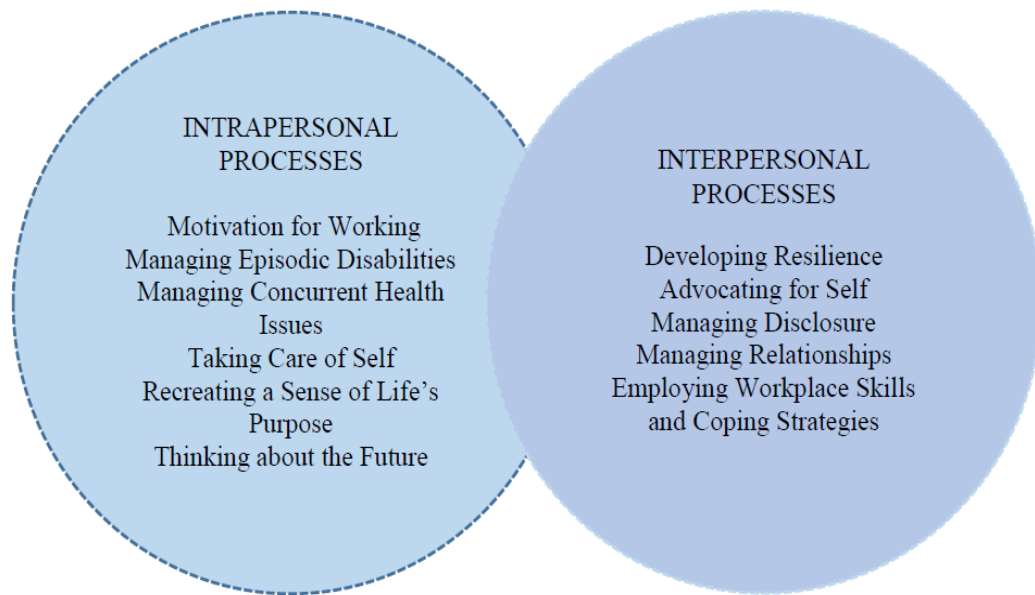
Fig. 5.1 Key personal level processes characterizing successful employment for people living with HIV

5.2 Intrapersonal Processes

The first major category in this conceptual framework is intrapersonal processes. In ecological models, intrapersonal processes are those primarily related to an individual's knowledge, attitudes, skills, self-concept, health, and behaviours that influence success in the labour force (McLeroy et al., 1988). Study participants reported a variety of intrapersonal processes related to health and personal psychology that they perceived as important in contributing to their success in the labour force. These were the motivation to work, managing episodic illness, managing concurrent health issues, taking care of self, recreating a sense of life's purpose, and thinking about the future. Each of these subcategories will be discussed in the following section.

5.2.1 Motivation for Working

A variety of motivating factors and the meaning individuals attributed to employment were important considerations for study participants in the context of HIV and labour force participation. Given the oft discussed risks and challenges attributed to labour force participation for participants, a series of strong motivators were often important preconditions to employment. Study participants described a variety of intersecting social, emotional, and financial reasons for participating in the labour force. These are described in a series of six interrelated properties. These properties are feeling healthy, being passionate about work, creating financial self sufficiency, preventing social isolation, learning and growing through work, and protecting self from the psychological impact of illness - each of which will be discussed in the following sections.

5.2.1.1 Feeling Healthy

A common factor motivating people living with HIV is the belief that labour force participation supports improved health. For instance participant 30 attributed health benefits and longetivity to the cognitive stimulation he received through his job in the education sector:

> So I feel it is important for me also to continue working and
> stimulate my mind. I am 62 and I feel that I know quite a bit about
> HIV and about you know how it affects the body, the mind. And so
> I am really, kind of, I guess doing what I call preventative
> medicine by studying, by learning. I wanted to create an interesting
> life for myself you know what I mean?

For many participants in this study, feeling healthy, having energy, and not experiencing major episodes of illness underlined their motivation to work. In this respect, participant 2, a gay men living with HIV for several years expressed this simply, "I can get up every morning, I can go to

the washroom, I can, you know, I can go to the gym, so why can I not work?" This sentiment was echoed by participant 17, also a gay man:

> Um, I just, even, God forbid, unless I become really ill or can't
> work at that point, that's different. But for now, while I have the
> ability, and nine times out of ten, the energy to do so, I want to.

In some cases these feelings were tempered by uncertainty regarding disease progression and experiences of illness. Despite the burden of illness many participants remained motivated to continue working. Participant 10, a single mother, acknowledged struggling with health issues and caring for her children while still maintaining a motivation to work. She stated simply, "Sometimes it is hard to work, but you have to do it". Others experienced serious episodes of illness; however this did not dampen their motivation to work as soon as they were feeling better. In fact, several participants were determined to work as soon as their health permitted it. Participant 17, a gay male working in health and social services, discussed returning to work after a serious HIV related illness:

> So I was working full-time at that time and then as I got sicker I
> worked less, and then it got to the point where I didn't work at all
> and I was on meds. I still am on meds, the first regimen I was on
> was AZT [early HIV medication] which was really debilitating and
> then when I switched off the AZT onto the other one I became
> much more functional and started to volunteer, and then I just
> jumped right into full-time work.

Feeling healthy and able to work was motivation enough for many participants, even those who had experienced bouts of debilitating illness.

5.2.1.2 Feeling Passionate about Work

Secondly, many study participants credited their success in the labour force to a passion for their job, and a simple love for the work they do. As will be discussed in following sections, living and working with HIV posed many challenges at the personal level. Nevertheless, many

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study participants were strongly motivated by a passion for their work. Being engaged in work that they loved to do and felt strongly about was a factor that inspired study participants to continue with employment despite the obstacles. A sample of participant narratives featured brief but compelling comments that attest to this passion, "I am very outgoing. I love people. When I get a job I do it with all my heart. I love working", "My career was like a gift sent from God", "Yes, it's the first time in my life I ever said I love my job", "The passion I have for my work, I pass it on to others and I get just as much out of it myself". While study participants reported a variety of different types of jobs they were passionate about, connecting with others was a factor for some. For instance, participant 3, a young gay male, stressed the value of working with other people as a factor that contributed to his enjoyment while working as a bus driver:

> I enjoy driving; I have a clean driving record. I wanted to just be outside more and that was the major factor, was to be outside, and you know have more dealings with people one-on-one. Whereas in an office administration environment I never had much dealings with people one on one.

Participant 22, an AIDS service organization support worker, further described how the work he loves was frequently connected to being with other people:

> Yeah, I've been employed all the way though. I mean the thing that keeps me employed is the joy in my work. So if I can stay happy where I'm working, I'm happy. And if I'm working with a good group of people then I'm happy.

Working in jobs that provided opportunities to connect with other people was one way in which participants were better able to deal with the social isolation that is closely associated to living with HIV. Indeed, social isolation was a recurring theme and will be discussed in detail in following sections.

Certainly, this passion for work among participants was linked to finding an appropriate vocational fit and a reasonably supportive workplace environment, advantages not shared by all study participants, as will be discussed in following sections. However, some participants described being willing to leave positions that did not connect them to work they were passionate about. Participant 17 described how, for him, motivation was the solution to finding the right vocational fit:

> Paralegal, it wasn't a good fit. I was doing it for the wrong reasons.
> I was doing it to please a family member… And so now the work
> that I'm doing is a very good fit, and ergo I love my job.

Additionally, participant 2 described leaving a job in a coffee shop for one that better engaged his creativity and passion:

> It's something that I love to do. I've always loved to be a designer.
> I've always loved to, you know, pull ideas from somebody to make
> something beautiful out of that. And that's what I love to do, the
> people are so friendly and the clients, they're really good so that's
> good stress. But, like, you know, dealing with people that are
> unhappy with their coffee, or dealing with little girls from high
> school bitching about, you know, I just don't like to work at 5
> o'clock. It's like, oh my God, like, you know, leave me alone.
> Like, there's the difference.

In summary, for a subset of participants, having or finding work that they loved to do and were passionate about were factors that motivated participants to continue working. Frequently, for a number of participants, these were positions that brought them into contact with other people and that assisted in countering the social isolation often attributed to living with HIV.

5.2.1.3 Creating financial self-sufficiency

The third property within the motivation to work subcategory related to participants' need to create an increased sense of financial self-sufficiency through employment. For many participants the motivation to work was attributed to a general feeling of wanting more from life.

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For some, work was seen as a means to a better life, more independence, and increased

resources. For most participants, the only real alternative to employment was dependence on

public income support programs and disability benefits, neither of which offered the financial

security and emotional quality of life that many seemed to aspire to. Participant 22, a male

immigrant to Canada described a sense of wanting more than living on public benefits could

provide:

> Why not just stay at home taking care of yourself and volunteer or
> do whatever? Just to be distracted and being happy with learning to
> live with what you are getting from all this. That was not my case,
> I was feeling like I wanted more. I have dreams, I had these
> expectations of my coming here, and my expectations were not just
> getting set up and living from an ODSP [Ontario Disability
> Support Pension] cheque.

Linked to this quest for a better quality of life was the opportunity to become financially

self-sufficient. A majority of participants spoke of the need to create increased financial

independence through employment. These participants perceived work as a way of escaping the

poverty associated with income support programs and a means by which to financially support

themselves and their families. This was especially true for some of the women in the study who

reported additional financial burdens associated with caring for children. Two participants (4 and

5), both sole support mothers, described the importance of successful employment in providing

for their families:

> With money coming in at the end it helps me to have a better life.
> It gives you money. When you have money you can do whatever
> you want for yourself. When you stay home it is really difficult
> you can't do what you want to do. You are limited; you have to get
> by on what they give you. But life is not like that, you have to try
> to move on and be better.
>
> I have to support my household. It's Maslow's hierarchy of basic
> needs, I need shelter, I need food, I need to keep my kids sheltered

and keep food in their belly, and unless it comes to a dire condition
that I cannot work then we'll move to recover disability as those
resources are available but whatever isn't going to kill me only
makes me stronger and until that point…

Additionally, for participant 11, also a single mother, the need to support family members

included extended family and out of country remittance payments, responsibilities that demanded

considerable resources. She described these added financial responsibilities, "I am working

because I have my kids, I have my family in Africa that I have to support. I have to support my

mom and my sisters."

Furthermore, for many participants a better quality of life meant more than just financial

independence. Many identified a variety of social and emotional benefits which they attributed to

earning their own money such as being productive, being independent, feeling safe, feeling

secure, not taking charity, and earning your own money. Participant 5, a single mother, described

these associated feelings, "You see the money deposited into your account, you feel safe, secure,

that it is mine I got it with my own ten fingers, it is not charity, it is my money." This was also

reported by participant 16, a young gay male:

It's just to be self-sufficient. You know, it's kind of a source of, or
a sense of pride when you can say, you know, I bought this, or I
bought a car, or I bought a house, or I bought this and I worked for
it.

Others described the sense of motivation and pride that came from having more money.

For some participants the losses associated with an HIV diagnosis, above and beyond their sense

of health, included an adequate income and subsequent access to appropriate safe and secure

housing. Working successfully was one means to reestablishing themselves, reversing these

losses, and regaining their quality of life. Some participants had incurred high levels of debt

during times of illness and disability. Employment reportedly provided participant 15 with some

relief from his creditors:

> And when I became ill, I actually had to sell my condo. Different
> things like that. And I depleted my savings, I barely have anything
> left. But the finances are finally coming back. I've seen an increase
> in my account from the negatives. That's one of the huge big
> motivators. Huge. It's amazing how much finances can impact
> you in all aspects.

Thus, for many participants, quality of life was connected to the increased access to

power and choice that, in Canadian society, is associated with earning your own money.

Participant 9, a gay male working in health and social services described being motivated by the

sense of personal power and agency he felt when employed:

> Some sort of satisfaction and dignity that I'm completely
> independent. I don't have to answer to anybody on ODSP [Ontario
> Disability Support Program] and I don't have to, you know, if I
> don't like a situation I have the power to get up and change it. So,
> uh, the power of choice and decision to move ahead.

For some this sense of power included having a measure of control over one's physical

environment and the various rewards that accrue to the status of being employed in the Canadian

economy. Participant 17, a young gay man working as a waiter in the hospitality industry,

described how employment can lead to increased resources, enhanced housing options, and a

subsequent better quality of life; options he was willing to work hard in order to keep:

> I actually own my own condo and I was able to do so because I
> worked my, pardon my French, ass off for about the preceding four
> or five years. I was able to save up enough to buy my own place.
> It's a very small one bedroom, it's very modest, but it works for
> me. Um, could I do it all over again? Now that I have HIV and
> now that I am just a few years older, working forty-five to fifty
> hours in a restaurant a week, probably not. But I got it. So, I work
> hard to maintain it and, to be quite frank, I do have to pick up
> shifts and when I'm feeling good at work I do have to stay on and

> take those extra tables to make ends meet. It's a little tough, but
> um I don't want to lose my quality of life.

While not all participants found themselves further ahead financially due to employment, the expectation of financial self-sufficiency was still a prime motivator. For example, participant 4, a single mother working as a laborer, acknowledged not making much more than she would on public benefits. When asked if she had more income from working she responded, "Yes, but not a lot more. It wasn't the money, though, I just wanted to work and have more than I did and save." This was echoed by participant 28, a gay male working in health and social services. He described deriving only a slight increase in income due to employment, but a strong sense of independence:

> The difference of returning to work has made me sometimes only a
> few hundred dollars financially, because of not having a subsidy
> anymore, but I go, "Wow, that's my money." So as a result of it I
> am, you know, not dependent.

In summary, many participants viewed work as a means to escape poverty and the limitations of income support programs, to support themselves and their family, and to create increased financial independence and quality of life. Wanting more for themselves financially was a frequent motivator, particularly for those participants not fulfilled or satisfied with their quality of life while receiving income support and disability benefits.

5.2.1.4 Preventing Social Isolation

An additional factor motivating many participants to work was the need to prevent social isolation. In addition to financial motives, many participants reported choosing to work in order to combat the perceived negative emotional and health effects of staying at home. For many participants, employment was a critical means to social inclusion and several described a strong

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desire to work rather than stay home where they reported feeling isolated, lonely, and unable to contribute to community life.

For some participants, the thought of staying at home was untenable, as described by participant 10, a recent immigrant to Canada and a single mother recently diagnosed with HIV. She said, "I have to work because I don't want to stay home. I hate it, it is so lazy." Many participants elaborated on this feeling, contrasting the connectedness they feel at work with a sense of social isolation they experienced when they were unemployed and relying on public income supports. Participant 17, a gay male working part time, described the impact that social isolation due to unemployment, had on his mental health:

> While I was on ODSP I was self isolating and dealing with
> depression. I withdrew from my family and friends and the world.
> I lost a lot of social skills which are now coming back. It was a
> very dark period.

This was echoed by participant 14, a 38 year old gay male, who also reported a sense of social isolation when not working:

> *Participant*: I would certainly choose to work. If I was offered just
> to be paid for sitting at home, I wouldn't choose that. I do want to
> work.
>
> *Interviewer: What is it about not working that you don't like?*
>
> *Participant*: Well, first of all it just makes you unmotivated and
> lazy, and you just don't have a desire to go out and do things with
> people. It makes you feel isolated if you're not working.

A common theme, first identified in the feeling passionate about work subcategory, some participants described increased social inclusion including interacting with others while at work as a motivating factor. Participant 5 reported feeling as though she had no option but to work as the idea of being isolated at home is one she just couldn't consider:

> If I had to stay home every day I would lose my mind. I need the outlet, I need to be out in the world and circulate myself because being at home with four walls can do to the mindset not very good. Even if you have a computer and you're sitting at home. I just like the interaction.

Participant 31, a community activist and long-term survivor has witnessed the impact that HIV has had in the gay community for over 15 years. He described what he felt were the serious health and social consequences for those friends living with HIV who have been out of the work place and socially isolated:

> I see people in the HIV community; I see that cognitively they start to kind of slide. You see depression is pretty common and I see they kind of also, it's like you know, they go on long term disability and some of them end up doing nothing and get hooked in the system. Sometimes it's like everyone is doing everything for them, but it's like they become passive. Life has less meaning. Also cognitively they are not stimulating themselves. I have seen people kind of slide. I brought that up at a meeting and people tell me I should not be talking about that. I see people dying and I am thinking they were not that sick, they were sick, but not that sick. What's happening is they are not feeling that great, they are living way below the poverty line, they have nothing in their life, their life is sort of meaningless, and they have people just looking after them. They spend time lying in bed, watching TV, they start missing doses of meds they end up in the hospital and the doctor gives them this big lecture, then they end up back at home. Then you see this notice that they have passed away. I think it is more common then we know.

The adverse health effects of staying at home was also discussed by participant 18, a Trans male working part time in health and social services. He explained, "I didn't do anything for 2 years after I tested positive. I just kind of mellowed out at home, thought I was going to die. I had to snap out of it and get a job." This was also described by participant 2, a young gay male who was recently diagnosed with HIV:

> Staying at home, I think, is ten times worse, because I get very antsy. I can't sit down… I like to move around, I like to do stuff. I

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like to keep busy. I just, I'm not a person that can sit down so, you
know, I think that would be more detrimental to my health because
it would stress me out more by sitting around and doing nothing.

In contrast, some participants described feeling much better while employed and reported

social and emotional benefits as primary motivators for employment. For instance participant 13

reported feeling more active and connected through his job:

I like to be out, and being active, and being useful. I can manage
myself doing something to feel good. Now that I am doing the job,
I am doing, I like it because I don't have to be at home.

Participant 10 also reported combating the social isolation attributed to being at home with

participation in the labour force, to which he attributed psychological and emotional benefits and

a renewed sense of hope for the future:

I guess the benefit is being more in society because when I was not
working I was sitting in the apartment. I did not have any money to
go do anything. Being out and interacting with others, again self
esteem, self worth. And a better sense of what my future can be, as
opposed to what it used to be a few years ago.

In summary, several participant narratives described employment as involving more than

just financial considerations. In addition to the financial benefits received through employment,

the motivation to work also appeared to be connected to negative psychological and emotional

experiences many participants endured during periods of disability and social exclusion. Thus,

for many, employment existed as a route to increased feelings of social, emotional and

psychological connection that combined, helped to prevent their continued social isolation.

5.2.1.5 Learning and Growing Through Work

The fifth property in the motivation to work sub-category is learning and growing

through work. A common factor motivating many participants to continue working was the

opportunity to learn new skills or knowledge on the job. Many study participants acknowledged

that employment provided them with experiences that allowed them to learn more about themselves, meet new challenges, and develop personally. Indeed, a keen interest in learning was a common underlying characteristic common to a majority of the study participants. This interest in learning in turn supported their success in employment and assisted some participants in developing further career opportunities.

Regardless of the type of job, an interest in learning was frequently reported as a primary motivation to work and as a factor that could influence the type of work participants chose. In some cases, as with participant 17, learning and personal development were connected to developing a career and making a contribution to community life; frequent themes that will be explored throughout several elements of this framework:

> But the financial part doesn't really weigh heavily for me it's more how do I feel just as a person who's contributing to society and interested in personal development and community development. I now have the feeling of contributing to society, locally, globally. Also because I'm doing front-line work now it's making a change on an individual level. Personally I'm growing all the time, the learning curve isn't as steep as it was originally but I'm still learning a lot so there's the personal development as well as intellectual development as well as career development. It sort of fits all of those things.

Certainly, the opportunity to learn and grow through work was more common among those participants who were in supportive workplaces and professional positions. Nevertheless, a desire for fulfilling vocational opportunities that provide learning experiences was also reported by participants working in jobs that they didn't find satisfying. Participant 5, a recent immigrant to Canada spoke about leaving a difficult position in the hopes of finding one that would provide her a better opportunity to learn new skills and improve her qualifications:

> Right now I want to find someplace during the summer that will help me find a job part-time in the evening and the job won't be too

> hard because doing cleaning is too hard and you come home and
> you are tired and I wasn't enjoying it. It was money and experience
> but it didn't help to improve my English. I would like to do a job
> where I can put into practice my English speaking and writing and
> to increase my skills. There are so many things that need to
> change. My whole problem now is that English. It drives me crazy
> but that is my problem, and all my prayers are to have the strength
> to do that and improve and do what I want to do in the future.

Furthermore, some female participants reported compromising their opportunity to learn for jobs that provided financial stability and the ability to support their families. However, despite this reality, many still reported feeling motivated to find challenging and stimulating jobs, as did participant 24, a married women raising children and working in the family business:

> I would like to do work that I feel is meaningful and making a
> contribution and that challenges me. You know that's the problem I
> have with the current arrangements is that I'm not necessarily
> learning much… I want to feel like I'm keeping learning. I want to
> feel like I'm learning new things and new ways of doing things and
> making a contribution. I think those are the two main things that
> drive any of my shifts in the kind of work that I do.

Thus learning new skills on the job and growing both personally and professionally was an important motivator for a wide diversity of participants.

As part of this focus on learning and growing, it was not uncommon for participants to alter their vocational motivations and goals following diagnosis. This phenomenon was reported by several participants and will also be discussed in following sections. However, in relation to motivation to work, some participants acknowledged seeking vocational opportunities that allow them to learn new skills as a key part of the transition to new, post-diagnosis vocational identities. Participant 8 aptly described how exposure to illness altered his vocational motivations and led him to seek new learning opportunities. Previously a health professional, he

retrained as a social services worker in order to fulfill a passion for working with people in a

different way:

> So I was put on disability. I was very deathly ill. I was quite ill. So
> during the recovery time, I did some soul searching and so what do
> I really want, you know what do I want to do? You know, I want to
> get back into the workforce, but I just don't want a job. I want
> something that really motivates me, something I have a passion for
> and something that is uh worthy. So, um, I thought well this
> doesn't require an EMS [emergency services] approach, this
> requires a social work approach... So, I mean, I had to change my
> whole way of thinking about trying to fix people as opposed to
> support them, guide them and, um, advocate for them. So, it's
> changed my whole perspective.

Participant 30 also described how living long term with HIV has led to a career change and a

differing set of motivating factors that require openness to learning, growth, and change. For him

this meant becoming an Instructor after years of providing direct services to the public:

> I teach part time at a few colleges. I also pick up other work, I see
> some clients and that's about it, that's what I do. I have been doing
> that, teaching for approximately 8 years. It is the second career I
> have developed because of my HIV status. My gut feeling was my
> original career was not good for my health. It is stressful, it's
> demanding.

Thus, in addition to the financial and social reasons for working, many participants in this

study reported learning and growing through work as a key motivator. This did not come without

certain challenges, an aspect of work that some participants seemed to welcome and were proud

at having met. Several participants acknowledged thriving on the sense of challenge that comes

with learning on the job. Participant 1, a civil servant, attributed his success to his ability to learn

and meet challenges. He described himself as, "The type of person that my employment needs to

be a challenge." Additionally, some participants spoke about struggling with challenges as they

learned a new job or planned for a future vocational role. Participant 19 is a male who

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transitioned from living on the street to a professional role in a health and social services agency.

Among the many challenges he faced was learning to work with technology:

> When I first applied they had me do a proposal on a lap top
> [computer], I had never used a lap top in my life. The thing went
> blank - my boss was like "What is this?" I said, "I have never used
> a lap top, it's a status symbol". He gave me 24 hours and I
> presented it the next day and I got the job. Now I know how to use
> a lap top.

A determination to learn was also expressed by participant 24, a married women raising children

and working part time. She was clear that part of her motivation to work was being able to learn

and develop a contribution to the community. She explained, "I want to feel like I'm still learning

and that I'm contributing that really is the drive for me."

Regardless of the type of occupation or life circumstance, many participants desired

vocational opportunities that allowed them to learn new skills and knowledge, and to grow

personally through facing challenges at work. This perspective introduces a key theme, that of

participants as willing learners; one that will be evident throughout other findings from this

study.

5.2.1.6 Protecting Self from the Psychological Impact of Illness

The final property related to motivation is work as a means of protecting self from the

psychological impact of the illness. Many participants described engaging in their work to

protect themselves against the stress associated with episodic illness and to prevent them from

focusing on negative events in their life. Participant 1, a professional, reported that work kept

him busy which in turn prevented him from focusing on life stressors and the negative impact of

HIV. To him work "was something to keep my mind on something else". This was also the case

for participant 7 who explained that work "has stabilized me. Because the emptiness of having

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time on my hands just made me resort to thinking and stressing. Right. But this actually gives me purpose and, and I think it has, I know it has helped". In this manner, work served as a coping strategy, one that assisted some participants in maintaining a positive frame of mind. The mental health benefits associated with having a purpose and keeping busy were echoed by participant 4, a young gay male, who, in addition to HIV, had been struggling with serious mental health issues for several years:

> Yes, even just to keep myself busy because I was finding myself just sleeping till noon and not having much to do. It wasn't contributing to my positive mental health status. Just having something to do, and I mean, I say a lot of times if I was winning the lottery I would still want to work even just part-time, just to keep myself busy.

For some, the structure and routine that work provided contributed to this motivating factor. Participant 15 described how introducing a sense of routine into his life after several years of being ill was part of what motivated him to work:

> But also there was no routine in my life. So the routine of actually having to get up, having to be at the subway or get on the bus, that type of thing, having a lunch hour, and being, like you know, you have to eat now cause you're going to starve in a couple of hours - that kind of aspect has been good for my overall health.

As noted by participant 13, in addition to providing a positive coping mechanism, work was also a place to hide and avoid dealing with serious issues. A waiter, he described using the physical business of work to hold on to a semblance of normality despite his diagnosis:

> I was working, working, working. I was working because I did not want her to notice that I was, why are you still working? I did not want to tell her what I was going through, it was hard for me. But working, working, working, I was busy and I did not have time to think about the HIV or anything. I used to go to therapy at the same time. It was like for me I was not I did not have anything. I was okay but I was in denial.

Connected to the idea of work as a distraction from the illness were the other positive

psychological motivations that participants attributed to work. For example, several participants

described work as a core activity that helped them feel more in control of their illness.

Participant 2, a young gay man working part time while training for a new career, expressed a

determination to work as a way of maintaining control over his life:

> I'm healthy, I'm insanely healthy and, you know, I don't think
> there's any need for me to sit home and I just can't do it either,
> you know. This is not something that's going to take over my life.
> I can still work, I can still breathe, so I can still do my job.

For some participants the motivation to work was connected to preventing HIV from further

defining who they were as people. Again, participant 2 described this symbolic aspect of work in

his life:

> I'm not a person that can sit in a corner and cry about something.
> It's just....HIV is never going to affect my life in a negative way.
> I'm never going to allow it to take over my life and I feel that
> because I am positive and if I sit in the corner and say "I'm not
> going to work because of this" it's kind of allowing me...it's kind
> of allowing the disease to beat me and I refuse to do that. I need
> to be able to ...you know, I can get up every morning, I can go to
> the washroom, I can, you know, I can go to the gym, so why can I
> not work? You know. It also grows my mind; it also gets me to a
> new plateau. It just keeps me going because I won't allow this
> disease to beat me.

This is echoed by participant 26, a recently diagnosed gay male whose motivation to work was

connected to protecting his sense of identity:

> I just don't let it define me. I know that sounds cliché, so that's
> why I took the study and stuff just to get the message across. I
> think people should just watch themselves and be aware of it. I
> think work is great and I don't think people should define
> themselves by their disease. I totally believe in work and HIV.

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This dimension may be influenced by the length of time since diagnosis. Although not all participants in this category were recently diagnosed, those individuals struggling with issues of identity construction and those determined to "beat HIV" were more likely to have been diagnosed post 2000 and therefore may have experienced less episodes of illness and benefited from more effective medications. These factors may have mitigated the types of losses they have faced due to HIV, thus leading to a more empowered and optimistic approach to the illness.

Nonetheless, many study participants used work as a mechanism to cope with the many psychological threats HIV posed in their life. Summing up, participants reported being motivated to work by the need to maintain a sense of control over their life, safeguard their mental health, and retain a sense of personal identity in the face of HIV. Protecting against the stress associated with HIV was a primary motivating factor for many study participants.

This section discussed the six properties that comprise the motivation for working subcategory. Participants in this study were motivated to work by a variety of factors including feeling healthy, feeling passionate about work, creating financial self sufficiency, preventing social isolation, learning and growing through work, and protecting self from the psychological impact of illness. This set of motivating factors is a core intrapersonal construct influencing successful work trajectories for people living with HIV who participated in this study

5.2.2 Managing Episodic Illness

As discussed earlier (see Chapter Four), HIV has been characterized as an episodic illness. Many people living with HIV experience recurring and unpredictable periods of good health and poor health; factors that must be considered when addressing HIV and employment. Managing episodic illness is the second subcategory within intrapersonal processes. The episodic nature of HIV was discussed by many participants in this study who reported actively managing

episodes of illness as a key strategy for employment success. Specifically, they discussed a variety of properties, including experiencing debilitating episodes of illness at the time of diagnosis, managing milder episodes of illness in the workplace, experiencing illness as a result of medication, and working through episodes of illness as a strategy of coping.

5.2.2.1 Experiencing Debilitating Episodes of Illness at the Time of Diagnosis

For many participants, the most serious HIV-related episodes of illness they reported were at the time of diagnosis. Many participants describe the debilitating illness they experienced upon seroconversion (the point where the development of detectable antibodies to HIV occur in the blood as a result of HIV infection); extreme points of illness where some individuals were so disabled they were forced to leave the workplace or were hospitalized (Public Health Agency of Canada, 2009). It was not uncommon for study participants, particularly those with more recent HIV diagnoses, to subsequently receive an HIV diagnosis while hospitalized. For some, the emotional and physical impact of the diagnosis precipitated needing to leave employment temporarily. In a majority of cases, these individuals had no medical or long-term disability coverage, forcing them to rely on employment insurance or provincial income support programs. Several participants vividly recalled their painful experiences related to diagnosis. Participant 24, a married mother of two children described her experiences:

> I wasn't infected until a couple of years ago. We went on holiday and I came back and I thought I had malaria. It was really this sort of violent seroconversion that led to me not having any platelets and it was at that point that they said "You have to go to the hospital and stay here" and that is actually when I started to feel a little bit better, because they started giving me pills for malaria and pills for all kinds of other stuff. So they felt that I was seroconverting because I had roving symptoms that came and went… I could not have worked for probably three months I would say. I was sick for three weeks before getting to the hospital. I was in the hospital for 10 days or so and really then I was on steroids

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and I think that's what really did it to me the steroids really were difficult to get used to they were difficult physically.

Participant 15 recounted a similar experience:

One day I could not work, I could not work, I thought I was sick and after that I do not remember nothing else. When I woke up I woke up one month later in a hospital… I lost 20kilos of weight. There were needles here, a plastic tube here, a small… here. I just stay in coma one month. I have pneumonia. So that was the start. So they told me no, we test and you are HIV positive. So that was when my HIV life started.

Several participants attributed a temporary inability to work to the emotional impact of the diagnosis as well as the physical effects of illness. For participant 28, a health care worker with full benefits including long-term disability coverage, the emotional force of being diagnosed with HIV was the main cause of work interruption. In this case, he did not feel able to manage the process of requesting a paid leave from work:

Because at the time I was working, like I said, it was not within my head space at the time. It was unionized; I possibly could have gone on disability. But at the time, I was just, you know, I was just like I am leaving, thank you very much for the experience good bye. Because there was nothing in my capacity to deal with being diagnosed that I could have returned to and gone through whatever paper work that is necessary. To think about, it was kind of like almost like don't ask, don't tell kind of thing, just gone.

For many individuals, their HIV diagnosis came as a complete surprise. Some participants learned of their diagnosis during routine screening as part of the immigration process. Participant 6 discovered her HIV status through routine prenatal testing. She discussed how the shock of the diagnosis combined with her pregnancy made it very difficult for her to continue to work:

Um, after my diagnosis I stayed for quite a long time at home. Because, you know there was maternity leave. But I didn't do very well during my pregnancy because, uh, because it was a shock. And, I could have worked, you know, but I had to constantly take time off work, not because I was physically unwell, but I think it

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had something to do with just the shock of everything and how
reality struck.

While all participants were able to eventually make their way back into the labour force,
those in jobs with full benefits suffered fewer losses and received better workplace
accommodation. Participant 14 received long-term disability benefits while on an extended
absence from work and appropriate accommodation upon his return, factors that supported his
ability to manage a major episode of illness:

> There was a two year delay there while I was on long-term
> disability. I recently returned back in, the end of November, on a
> gradual return. I'm still kind of under the gradual return. I work
> three full days a week now instead of uh five days a week part
> time. And each two, every other week, every, bi-weekly, I guess,
> we increase another half day. So it's going to be a five day work
> week and it probably will be in existence full time I think in June.

Episodes of illness related to seroconversion and at the time of HIV diagnosis were some
of the most serious of those described by participants. Based on these vivid narratives, receiving
an HIV diagnosis was clearly a critical physical, emotional, and psychological experience for
many participants. Despite the severity of these episodes, all participants were able to
successfully manage the physical and emotional impact of diagnosis and make their way back to
successful employment. The majority did this with little or no workplace support or benefits,
relying on public income supports while recovering from illness. Due to the stigma of HIV and
the unsupportive nature of their workplaces, some participants left their jobs completely, finding
new employment when they were feeling better.

5.2.2.2 Managing Milder Episodes of Illness in the Workplace

As discussed earlier, disease progression, effectiveness of treatment, and subsequent
vulnerability to illness were all unpredictable factors making it very difficult to manage HIV in

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the workplace. Reflecting this unpredictability, participants identified a wide diversity of experiences related to episodes of illness. Some participants acknowledged experiencing illness that caused work absence; however, others reported having very few episodes of illness. When asked if they had had periods where they have been ill or off work due to HIV several participants indicated never experiencing this. For instance participant 13, a gay male diagnosed with HIV in 2009, reported experiencing almost no episodes of illness to date and no medication side effects. He explained "Actually, I've always been in excellent health. Even with the medications I am taking, they have no adverse side effects at all". Additionally, participant 20, a gay male and a newcomer to Canada, reported less workplace absences due to illness than his co-workers:

> I only take meds once a day. Other than that I am quite okay. I
> meet my physician once in three months. That is all. I think in
> some aspects I can even be more healthy. For example at work
> people will have flu in all seasons. I did not miss a day all winter
> long. In 11 months I did not miss even a single day for any reason,
> I mean only if it was a scheduled vacation. Other than that, I saw
> people collapsing next to me with flu's and complications.

Nevertheless this experience was not the norm. Some participants reported periodic absences due to relatively minor episodes of illness following that first and often very disabling illness. Generally, it appeared that these reported episodes of illness were less severe in nature and that with care some participants were able to successfully manage them and minimize their absences at work. When discussing episodes of illness, several participants noted difficulties related to the unpredictability of the disease. Participant 21, a gay male and also a newcomer to Canada, described his experience, "I know when I have been at work, that being at work sometimes my days are good, sometimes my days are not good, or sometimes I have long periods of pretty good health, and sometimes I don't have it." This unpredictability was

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reiterated by participant 12, also a gay male, who discussed the further impact of medication on

the already unpredictable nature of the illness:

> When I was taking medication I felt most of the time I did not have
> the energy to do anything. I had to be at home and I did not know
> what was going to happen the day after. Because on call you have
> to be serious when you say tomorrow I am going to work. I did not
> know if I was available the day after because of my energy. That is
> why I started to stop, to start saying no to him. At the same time it
> was not good for me, my boss needed someone who was available
> all the time. He could not count on me.

Finally, participant 6, a women working in the health and social services sector, illustrated the

additional stress and worry that even minor unpredictable episodes caused her when trying to

maintain employment:

> Like I said, you have seven, you can only have seven number of
> sick days right. And, sometimes you're sick, right, and then you
> know, you're concerned because you also have responsibilities.
> You're concerned about having to stop and do the employment
> record and go and retire your work and then you're concerned
> about how that will affect your income. So, ya, it is a lot of
> concern. Because it comes when you least expect it. It comes when
> you least expect it.

Regardless of treatment status and length of time living with the disease, several study

participants reported needing to find strategies for managing episodes of illness while

simultaneously working. This included minor illnesses that are not necessarily symptoms of HIV

but which, due to a compromised immune system, may progress into a more serious issue.

Participant 3 described his attempts to continue working at his part time job as a school bus

driver while dealing with migraines:

> I came down with this migraine and I never experienced migraines
> in the past and I was six days taking ibuprofen and by the fourth
> day I was worried about it, so I went to the hospital to get it
> checked out and they sent me for a CT scan and nothing came back

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> abnormal. They just give me something stronger than ibuprofen
> because I was taking 4 ibuprofen at once to get through it, and they
> gave me something stronger so I didn't have to do that and by the
> time I made it to see my family doctor it had passed.

Additionally, participant 17, a gay male working in health and social services talked about anticipating episodes of illness and finding ways to ameliorate these with alternative forms of health care:

> My biggest challenge is around health. I get sick for about four
> days and I am averaging once a month for the past year and a half.
> So that is my biggest challenge, trying to figure out what's going
> on there so I've seen a naturopath and they suggest I need to eat
> more protein so I'm doing that but I will see what happens.

Whether directly related to HIV or attributed to the medication, fatigue was an important physical challenge facing many living and working with HIV. Study participants frequently described lack of energy and fatigue as illness related factors that impact their performance at work. Several described struggling with episodes of extreme fatigue while at work and afterwards. This was a challenge for participant 12, a waiter, who briefly described the effect that medication had on his life and ability to work. He reported, "When I was taking medication I felt most of the time I did not have the energy to do anything." Managing fatigue was a constant concern for many and at times harmed their performance on the job. Participant 8, a financial services employee, articulated the stress he felt related to managing this fatigue and its effect on his performance at work:

> I would be tired all the time and then the next day I'd get to work
> and I couldn't keep up. You'd think when you're using a computer
> you don't have to be quick on your feet but you're doing these
> crazy hours, uh, you can't do your job.

Additionally, participant 22 described how a combination of anxiety and fatigue affected his ability to concentrate on the job. He explained, "I mean concentration most of the time is a

challenge for me. But when I'm having high anxiety or things are pushing me I lose my ability

for focus, I lose my ability to finish." For many of the women who participated in the study,

fatigue was exacerbated by the multiple demands they faced as family care givers. Participant 6,

a single mother and professional working in health and social services described the effect that

fatigue had both at work and in caring for her children:

> But then I'm responsible in making sure everybody's needs are
> met, and it takes a lot of energy. And, one of my biggest side
> effects with my medication is fatigue. So after work, sometimes I
> can't give out anymore, right. I barely have enough for myself.

This experience of multiple demands was in contrast to the experiences reported by the male

participants, none of whom were caring for children or assuming a role as a primary caregiver.

Managing this fatigue was a critical factor in maintaining successful employment. Study

participants identified a range of strategies they employed to deal with this issue and keep their

jobs. For some, fatigue was the reason they chose part time employment over full time work, an

option that left them more time to rest and care for themselves. Participant 24 recalled how the

flexibility of working part time in the family business allowed her to counter the fatigue she was

experiencing:

> I think I still could do some things but certainly not full-time you
> know. Maybe like five or six hours a week. I could still drive, that
> I could still do. I just needed to sleep a lot for some reason. I had
> long afternoon naps and then I would go to bed early at night. It
> really restricted my level of activity for sure.

Participant 6 also opted for part time work as an explicit strategy to manage the fatigue she

experienced:

> The actual illness is, you know, like, the on and off illnesses, came
> when I started working, because then, you know, I was now on
> stable medication and, getting used to the medication, which is
> why I opted to choosing a part time job. You know, because I

could regulate my hours. Mornings were really tough. So, although I was working in an environment where they were sensitive around the issue it was still tough. And sometimes by three o'clock I was totally drained, washed out. So I opted for a part-time job.

Prioritizing self care was also identified by study participants as an important strategy.

Participant 1, a 58 year old male who had been in the same professional job for 30 yrs, explained

his strategy for effectively dealing with fatigue in this manner, "I have lower energy. My energy

level is not as high which may account for being careful about the stress level, being careful

about interruptions, eating properly. Trying to maintain proper sleep is a must." In cases where

fatigue was being caused by HIV medication, being informed about treatment options and

proactive about self care was an important strategy utilized by some participants. Participant 31

discussed how actively engaging with health care providers and managing his diet led to

increased energy on the job:

> One of the biggest challenges I have experienced recently in terms of being HIV positive and working has been the fact that one of the side effects of my meds has been my phosphates are low. One of the drugs depletes my phosphates and what I have noticed with that when my phosphates are low my energy level is low and it gets to the point where it gets hard to think because brain thinking actually takes ATP and actually means that you need energy to think and so it was interesting to me when the blood work came back and the pharmacist sat me down and said "Your phosphates are low, these are some foods to help with it." I am like, okay, so I literally started working on developing like a whole diet around my work so that I was replenishing my phosphates through my day, and through my work week. Because that is where I noticed it, I didn't notice it when I was off, I noticed it when I was working, because that's when I needed it, because that's when I am thinking and running around and working. So it's like okay and so I developed it, and it really helped a lot and made a big difference.

Thus, for most participants managing episodes of illness in the workplace was a considerable

concern.

5.2.2.3 Experiencing Illness as a Result of Medication

Many individuals reported that episodes of illness were often caused by starting or changing a medication regime; periods where debilitating side effects can be at their worst. Successfully managing these scenarios were important factors in maintaining labour force participation for many participants. In particular, several participants described the adjustment period following the start of a new medication as a sensitive time and one that often led to episodes of illness. Managing these episodes posed a challenge for many participants. Participant 16, a waiter in his 20's, spoke of the difficulty in working a very physically demanding job while adjusting to HIV medication:

> In terms of side effects I think I got off a little lightly. But I did have joint pain and that is a known side affect for one of the medications that I take. And the joint pain lasted for a good week or so in the very beginning and I worked at a two floor restaurant so it was a little trickier. I did have to slow down and go a little easier in the beginning. As well, my stomach was a little off in the first few weeks or so and, of course, when you have stomach pain, you're not the best at work because it's very discomforting.

For some, as with participant 14, this adjustment period was so physically and emotionally difficult that it caused them to stop medication temporarily, which in turn led to poor health

> I'm very sensitive to medications. But ya, it was sensitivity to meds and the whole emotional aspect came into play and then the physical.... and, and I just... became a different person. And I wasn't able to focus on work. So I stopped taking meds because the meds were so impactive on me and my counts dropped below one fifteen and stayed there for a while. I became ill often and just the whole overall well being was affected so I just said, "okay, just take it long term and see what happens."

In addition to the adjustment period, many participants reported a variety of enduring side effects that they were managing while working. These included gastrointestinal problems, rashes, nightmares, nausea, drowsiness, low energy, an inability to concentrate, insomnia, impaired

memory, and diarrhea. Some participants reported seeking flexibility in their schedules in order to accommodate medication side effects, while others timed the taking of their medication so as to minimize the impact of side effects while on the job. Participant 7, a part time employee working a variety of shifts, described trying to time his medication with the unpredictable hours he works at his job:

> I had been on my meds for at least 9 months and I kind of had coping mechanisms on how to manage it. You know, I knew it meant for me to cope and manage to be functional at work by nine I had to change morning meds maybe to, like, 6 a.m. so that it gave me that 2 hours in case I got sick.

Although a minority, several participants were not currently taking medication for their HIV. Some participants were on "drug holidays", managed periods of time in which they were taking a break from HIV medication. Others had not yet started HIV medications. In conjunction with her doctor, participant 24 temporarily suspended all of her HIV drugs as a strategy to help her cope with the issues related to taking medication. She explained her decision:

> I was on an incredible amount of drugs for probably about eight months they were worried about everything so I was taking six or seven different kinds of preventative antibiotics and then pills to overcome side effects of some of that stuff so it was sort of like a real challenge to keep track of all those drugs to take, most of which in retrospect I don't think I needed anyways… Just to give my body a rest. I think that I was really feeling like oh my God all these drugs I was taking and this is just one of them but I wanted to just kind of clear out of all of that I think that's pretty much it pretty much it. I can't really think of anything else that really spurred me to do that because I was tolerating it just fine.

Some participants noted the importance of planning for this adjustment period. Anticipating temporary side effects, informing one's employer, and scheduling leave were ways that participants successfully negotiated the difficulties associated with commencing medication while working. Participant 8 recalled strategies he employed to manage this process:

> I took some time off, actually, one summer. When I first went on
> the medication, actually, it was really bad side effects, I mean I
> was nauseous. I couldn't work. So, the initial summer I started on
> the medication I still remember that. I took the summer off and
> went to my manager and said, "Listen, I started on this medication,
> there's a lot of side effects, I need some time off". And she said,
> "Sure, take some time off", or whatever.

It is interesting to note that for those not yet on HIV treatment, the prospect of beginning a new medication raised uncertainty and caused a great deal of anxiety. Participant 5 discussed her feelings as she approached the beginning of treatment:

> The biggest, scariest obstacle to overcome is if and when I'm going
> to get introduced to medications and what type of effect will that
> have on me? What and how much time off will I require? How will
> I broach that subject? And I will work with my specialist in that
> regard, but I'm hoping that everything that I can take that it's not
> going to affect me that way. I don't know I'm hoping that with the
> technology that it's once a day that I can take it at night and sleep it
> off. I don't know what to expect that's the biggest obstacle that I'm
> going to have to endure in the next couple of months.

Thus changing and beginning medication produced episodes of illness that many participants struggled to manage while maintaining ongoing employment.

5.2.2.4 Working Through Episodes of Illness as a Strategy of Coping

Minimizing illness and working through illness were two connected strategies that many participants described utilizing in order to prevent absenteeism, safeguard their sick leave, and to deal with the uncertainty associated with an episodic condition. This final property within the area of experiencing episodic illness describes processes some participants enacted to ensure continued success at work. While not explicitly discussed, an underlying theme in some participant narratives was a tendency to minimize their episodes of illness. When queried, some participants denied experiencing illness but then subsequently went on to describe serious impacts of their disease on their health and their ability to work. For these participants,

minimizing the impact of their illness was a coping strategy that assisted them to focus on the

future and move forward in a positive frame of mind. For example, on several occasions

participant 5, a single mother working in financial services, described some serious and

debilitating symptoms, only to later normalize them and insist that they have had no real impact:

> Only as the effects are concerned is having a pounding headache;
> peripherals [job expectations] not being met. I felt out of whack.
> But did I let anybody know what was happening? No. Just okay
> no. I just don't feel well, let me work through this, and yeah there
> hasn't been any big impact.

> If I haven't had enough sleep to function during the day, sometimes
> that's a little bit off. Everyone has those days so I attribute that to
> everybody else. Yeah it's not impacted me so much.

Despite believing that HIV has had no medical impact on her life, this participant later described

feeling challenged emotionally at work. She expounded, "Concentrating on my job at hand, to

get it fulfilled for the whole day, although I could fake it really well I was having to leave and

cry and do my thing. But I say one day at a time." Participant 7 also expressed optimism despite

managing several serious health conditions and experiencing three HIV related episodes of

illness:

> I think I was fortunate, my first job back after my diagnosis and
> after my cancer diagnosis and the surgery. But you know I'm very
> lucky. I've got a good set of genes; I've had one really debilitating
> illness and haven't gone in and out of HIV related illnesses like,
> uh, just two or three times.

Normalizing the illness and claiming that it is not connected to HIV provided a measure of

comfort to participants who were worried about HIV disease progression. This was the case with

participant 29 who encountered some serious episodes of illness but took comfort in the

perception that they were illnesses that could afflict anyone:

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> The only illness I have had in my whole life was just a few months
> ago something called reactive arthritis, a bacterial infection. A 2%
> population, from what I've read, has a genetic marker so normally
> you just get a bacterial infection. Normally you just pass it and it's
> done, but it triggered this, and so I was in the hospital for a week
> and I am just finally getting over it because I was walking funny
> and this hand hurts. I always laugh because HIV had nothing to do
> with it at all. It was totally something out of the blue; it can happen
> to anybody at any time.

In addition to minimizing the effects of the HIV, many participants reported working during episodes of illness as an additional way of coping with uncertainty. In response to employer fears regarding episodic illness and absenteeism some participants described going to great lengths to prevent the perception of illness. Some participants reported working during episodes of illness because they had no sick leave and thus wouldn't be paid if they did not work. Others, who were in new positions or on probation were concerned that they would be penalized for absenteeism. Participant 16, a waiter described his reluctance and inability to afford being off work sick:

> In a restaurant there are no sick days. If you call in sick or just go
> home sick, unfortunately, you lose like a lot of money because it's
> not just your hours but it's your ability to make gratuities. So, in
> that respect, you know, you can go home sick or whatever, that's
> fine, but it's not in your best interests. So, kind of a bad. You
> know, sometimes I try to fight it, and a lot of servers do, because
> they know if you go home sick, there's no sick day, there's no
> nothing. There's no personal time or personal days.

Participant 3, a school bus driver described working with a migraine instead of risking taking the time off to care for himself:

> I mean being so new in employment I didn't want to take the time
> off, and when I came down with the migraine in March I started
> out with two ibuprofen which wasn't doing the trick to get me
> through, and by the fourth day, like I said I had to take four first
> thing in the morning. It's just I couldn't afford being off being so
> new in employment. I was still on probation. I didn't want to take

the time off. I was going to work right through it, and I did, and I was able to, thank goodness. They don't want you to take time off because you have so much other time to book appointments and do whatever else you have to do. So they don't look kindly on you taking time off, and so it was like, no, I can't take time off there's no question about it.

For those participants with better sick leave provisions and other workplace benefits, fear of becoming ill and uncertainty regarding the future led many to save up personal days and vacation leave in case they need to take time off for medical appointments or during episodes of illness. In many cases these participants described how they were denying themselves well earned vacations and holiday time, potentially stripping themselves of a valuable and needed time of respite and self care. Participant 6 described her strategy for managing her sick leave:

So, you can imagine, if I have ten sick days in a year and I have to use that to include my appointments, and I never got sick... whenever I have appointments I am going to try and avoid using it because I know I have this virus and I may get sick. So those days are like gold to me. So, there are times maybe that I might want to follow up on my appointments because I don't want to use my sick days. I plan my appointments according to, like negotiating with my, doctor. Can I come in on this Saturday? Can I come in at 6 in the evening?

Participant 7 also reported saving her vacation time in case she became ill:

For my appointment coming up in May, I've already booked vacation for that week, so I'm off, I don't have to contend with everything and go back to work. Ultimately after everything that's discussed after that appointment I may take more time off. I will cross that bridge when I get to it. It's all work and no play doesn't make for a fun day because I've only got three week's vacation. I just break it up over the whole course of the year and I hope it will just all work out.

Thus in this manner minimizing and working during illness were common strategies utilized by many participants to manage the uncertainty related to living and working with HIV.

Managing the episodic nature of HIV was a challenge being met by study participants. This key subcategory was discussed by a variety of participants who acknowledged experiencing debilitating episodes of illness at the time of diagnosis, managing milder episodes of illness in the workplace, and minimizing and working through episodes of illness as a strategy of coping. This section described these challenges and the skills and strategies with which they were met by participants, all key properties in working successfully.

5.2.3 Managing Concurrent Health Issues

Concurrent health conditions were additional factors that negatively impacted the employment trajectories of participants. For many participants in this study, HIV was just one of several health conditions that they were experiencing concomitantly. Managing concurrent health issues is the third subcategory within the category of intrapersonal processes. This section will discuss the properties of this subcategory including participants' experiences managing other chronic health conditions, cooing with mental health issues, and dealing with an addiction while living and working with HIV.

5.2.3.1 Managing other Chronic Health Conditions

In addition to HIV, some participants reported experiencing other chronic health conditions, notably cancer, high blood pressure, and Hepatitis. In some cases these health conditions interacted with the impact of HIV, creating complex obstacles to successful labour force participation; challenges that some participants struggled with. For example, two individuals, participant 18 and participant 19 were living with Hepatitis B and C, co-infections that had physical and emotional consequences. Participant 18, a transgender male spoke of the serious health impacts of his hepatitis co-infection. He explained, "I almost lost my liver from Hep. B. and then I contracted Hep. C. in 2004 and it was HIV at the same time". Participant 19, a

gay male from the Black community, described the emotional challenges he faced when dealing

with Hepatitis C, a co-morbidity relatively common with HIV infection:

> Because I had another problem, I was co infected with Hep-C. I
> blame myself. I was going through both treatments for HIV and
> Hep-C for 8 months before I started punching the wall. I never
> knew what Hep-C did to you. It gets you very angry, it gets you
> very emotional.

Other participants spoke of living with unrelated medical conditions that they viewed as having a

more immediate impact on their vocational goals than HIV. For instance, participant 11, a gay

male who had worked for years in the business sector, described the impact his impaired vision

had on his job search:

> I had been for a number of interviews in media and had disclosed
> my vision problem... I think I have had more problems with that,
> and no call backs, and things like that, because people feel that if
> you are working with numbers which is a lot of what I was
> interviewing for; the fear was this person might not be able to see
> and make mistakes.

Additionally, participant 7 discussed his experiences of working and dealing with cancer and

HIV; challenges he met with a unique sense of gratitude and optimism:

> I had major surgery in 2005. I had cancer. So I was put on
> disability. I was very deathly ill. I had esophageal cancer. So I lost
> 40 pounds. I was quite ill. But I was fortunate in some ways
> because I was young and healthy when I got the cancer and it was
> just a few years after my HIV. Everything was going for me other
> than the tumor.

In some cases, as above, treatment for these conditions contributed to additional episodes

of illness causing work interruption; challenges that many participants met with a determination

to continue working.

Thus, other chronic health conditions contributed to the complexity of workplace

challenges faced by several study participants. Treatment of these illnesses was also likely to

contribute to absences from work or periods of short term disability. In some cases, as will be

discussed in future sections, the interaction of HIV with other medical conditions contributed

important learning experiences, critical skills, and increased resilience enabling participants to

better deal with HIV in the workplace.

5.2.3.2 Coping with Mental Health Issues

Several participants reported managing the impact of chronic mental health issues while

working. For some, this involved a pre-existing mental health diagnosis, while for others HIV

caused or exacerbated current mental health issues or led to emotional distress. Regardless, the

presence of mental health challenges was common to many participants and was a further barrier

to successful employment. Throughout the study interviews, several participants disclosed

traumatic life experiences that led to chronic mental health issues, such as depression and post

traumatic stress disorder. For these participants, HIV intensified and compounded the distress

they experienced as a result of mental health issues. Balancing work with these combined

challenges was a struggle for some. Participant 12 described the chronic anxiety and fear that

returned following his HIV diagnosis and the impact it had on his ability to work and plan for the

future:

> I did not have any fear for many years. Lately, I can say 6 months
> ago, I started to feel fear for a lot of stuff. I am getting better but I
> don't know where I am going to be. I never thought that the fear
> was going to interrupt my development. It is like I stopped looking
> for my future because I am afraid what will happen. This fear
> stopped my brain, it is a life time goal what I am going through.
> For now I am still working on it, it has been so very hard.

Additionally, the stigma related to sexual abuse and mental illness created further workplace

obstacles and additional challenges that were being faced by several participants. Participant 1

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disclosed his struggle living with childhood sexual abuse and post traumatic stress disorder and

his subsequent efforts to contain and conceal this condition while at work:

> I've had life-long post traumatic stress since I was very young, and
> HIV has on occasion compounded that. When I was very young,
> for 6 years, I was molested by my grandfather. No one knew. I just
> didn't tell anybody, but sometimes this would come back to haunt
> me. My work didn't know, but we all knew there was a problem. I
> knew what it was. but my work didn't. So, I'd go to Wellness, but
> even when I went to Wellness I wouldn't tell them what it was.
> My doctor knew, but my doctor wouldn't disclose it. That was a bit
> of an issue. They just knew that something was wrong, and they
> were trying to find out what, but, nothing was going to give.

Several participants reported a connection between chronic mental health issues and the

HIV-related social isolation discussed earlier. In particular, some study participants revealed how

the social isolation they felt was linked to feelings of depression. Participant 14, a professional,

who in the past had been at home on disability benefits for several years, described this

interaction including the emotional and physical impact that the depression caused:

> It also made me depressed. There would be times when I would be
> out because I had a very small bachelor [apartment], and I don't
> like sitting around. I'd go for a beverage somewhere and be sitting
> there, and it made me very depressed because I would want to be a
> part of that. I would see clothes that I want to buy and can't. I
> dropped down to less than one hundred and ten pounds, I think
> partially, because of depression.

Additionally, participant 15, an immigrant working as a general labourer reported HIV, social

isolation, and depression as intersecting problems that made it harder for him to work:

> There are many psychological conditions that come with HIV.
> Depression is one of them. I live alone in Canada. I don't have a
> family, I live by myself. If you have a family around you have
> more to entertain your mind and to spend time. Living alone, I
> don't like to live alone.

The impact of HIV related social isolation was a theme discussed by many participants and one that recurs throughout the study.

For those without a specific psychiatric diagnosis, the difficult emotional toll of the disease still had a serious impact at work. Some participants underscored the importance of guarding against more acute forms of mental health issues. Participant 16, while not having a history of mental health issues, still recalled experiencing days where he felt down:

> So, I would say that overall I seem to be doing pretty well. But, you know, there are definitely, you know a day here and there, maybe once a week, maybe a couple times a month where either if I'm just not, if I'm feeling off or haven't rested well because I've been thinking about it a lot, um it'll affect how I work.

This was reiterated by participant 5, a single mother, who throughout her interview indicated feeling down and depressed due to the multiple burdens of living with HIV:

> It depends sometimes because I have my ebbs and flows and moments where I feel down. The best strategy for me is sleep, so if I have to sleep 15 hours for the one night then that's what I do to make myself feel better. Everything always feels better after I sleep… and you know sometimes you cry so much you get depressed but I guess it's my faith that it can't get any worse.

Proactively dealing with feelings of depression and managing other mental health conditions was a strategy many participants utilized in order to continue working successfully. Participant 4 described how in the past his mental health diagnosis contributed to periods of unemployment and difficulties returning to the workplace. Nevertheless he also reflected on what he learned from this difficult period, skills he applied in his current employment:

> My relapse in 2008 led to me being unemployed. I kind of, for lack of better words, went completely cuckoo, and I didn't do it very well. I could have handled it better if I had been on medication earlier, and recognized the symptoms, and spoke with my doctor, and gotten back on medication. I could have probably gotten away from what eventually ended up happening; me being unemployed.

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>It just got to the point that I just stopped going. I stopped waking
>up, I'd sleep till 12, getting there late or not showing up at all. I
>mean my mental health issues were really detrimental to my
>employment status.

Managing and preventing the depression related to living with HIV was a strategy many participants emphasized as important to their sense of well being and subsequent ability to keep working. Participant 23, a gay male in his late fifties, described working proactively to prevent depression:

>Everything that I was reading was telling me that the depression
>and psychological aspects was probably going to be the hardest
>hitting part, and so I was determined from the very start that the
>psychological piece had to be managed because I personally
>believe that you can make yourself sicker if you are mentally not
>dealing with things. Whatever it is, whether it's HIV or anything,
>with severe depression you can make yourself sicker or with the
>depression you can make yourself physically sick, and I've read
>some studies on websites and stuff that was saying that the biggest
>thing with people with HIV is depression, and so that was the piece
>that I was determined not to become depressed which of course I'm
>not.

Participant 28, a gay male working in health and social services advised finding support and taking time off as a means to actively managing the complex emotions related to HIV:

>If you are already working, and you are HIV positive, and you are
>thinking I can't do this right now, I can't wrap my mind around
>being diagnosed and being HIV positive and what that means, and
>you need to take time off - do that. Pull back, or stop, or get
>support: it's completely personal.

In summary, mental health issues were reported by many participants as concurrent health conditions that they actively managed while working. Whether having a specific psychiatric diagnosis, managing HIV related depression, or simply experiencing the complex emotions associated with living with HIV, these participants actively employed a range of strategies to deal with and prevent chronic and acute mental health issues. This active

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engagement in managing and preventing mental health issues was a common approach and assisted many to continue working successfully.

5.2.3.3 Dealing with an Addiction while Living and Working with HIV

Closely linked to issues of mental health, addiction was also identified by several study participants as an intrapersonal factor that influenced living and working with HIV. Of the four participants reporting an addiction, some stressed the importance of being in active recovery in order to maintain successful employment. Others working from a harm reduction philosophy stressed the importance of flexible policies and better accommodation at work as factors supporting their ability to continue working successfully. Either way, addiction was reported as an additional health condition that needed to be handled while working.

Several participants reported that their addiction had led to past periods of chronic unemployment. Participant 9, a gay male in his late forties, recalled how a serious addiction to alcohol led to him losing his job:

> Before that came about I had another fall out with the business, and I ended up in treatment. When I came back, it was a long time, and I did not know. Then I went out again about a month after the treatment; we call it going out. That was the end of the job. It was also my longest binge of 4 month of being sick. Oh my God, it was the last time I drank. It is the craziest illness you can get.

This was echoed by participant 29, a nurse, who also left employment due to psychosis attributed to his addiction to crystal meth:

> There was a lot of mess in my life, and I was fired from my job because things were a mess. I didn't know the system, I was crazy, I was completely psychotic and there is a whole long story around how that happened. I could not manage things very well so my boss had called me a couple times, and I didn't call her back and that was grounds for dismissal and I let it go. They wanted me to be drug tested, and I could not do that at the time so I went off.

For both these participants, dealing with their addiction and being in active recovery was an important precursor to successful employment. Participant 9 described how recovery from his addiction was a critical factor influencing his readiness for employment:

> I am also an alcoholic in recovery, five and a half years sober now. When I first got sober, I was not employable at that point because I didn't have the mental and emotional capacity to go out, settle in, and do it.

Additionally, two participants reported that access to workplace assistance programs facilitated their recovery by connecting them with rehabilitation programs. Participant 29 spoke about how ongoing treatment for addiction restored his mental health and assisted him in returning to his job. He acknowledged that maintaining these connections and his recovery were important processes involved in working successfully:

> I continued on with treatment for the two years, and that finished about a year and a half ago. I have not relapsed. I still am in recovery. It is very much entrenched in me, and I believe strongly in the principles of recovery. I would never use crystal meth ever again in my life even if they paid me for it. My mental health means so much, and I understand that the probability I would go psychotic again would be very high. I want to stay sane thank you very much. I stay connected with the recovery community, they [employer] very much connected me to that community, and I continue to go and you know work with that.

Other participants who reported histories of addiction did not abstain from all drug and alcohol use completely. Several participants stressed the importance of harm reduction policies and nontraditional workplaces as critical to their success in the labour force. Participant 19, a peer researcher, reported how the legal use of medical marijuana enhanced his appetite and enabled him to adhere to his medication schedule and his subsequent ability to be effective at his job:

> I went and got my own ATP [authorization to possess marijuana] card, and gave it to my supervisor and said, "Here you go." She does not smoke, she said, "What this is"? I said, "It is my authorization." She said, "Does that mean you will be stoned every day"? I said, "You read it. What do you think right"? But it does help me with my nausea and with my appetite. Today I did not smoke, I did not eat lunch, did not take my pills. When I smoke a joint before I go to work, by 11 I am munching at my desk. But I am eating, and taking my pills. If I didn't smoke it would be 5 o'clock in the evening and I still have my morning round in my hand.

Participant 18, a street outreach worker, also discussed the importance of a supportive workplace. He revealed that his workplace actively embraced a harm reduction philosophy, without which he would likely have been unable to sustain employment:

> If I was using weed and working [in a previous place of employment] I would be fired in a minute. But with these in Ontario, they are more lenient with you if you are using marijuana for your medication. Like if I smoked a joint before I went to work they would not even care. As long as it's not like you know cocaine or anything.

These participants worked in nontraditional workplaces such as AIDS service organizations and other health and social service providers that provided unusual flexibility so that people living with HIV and those with histories of addiction could access vocational opportunities. In these cases an explicit harm reduction philosophy allowed both participants to manage their addictions in an open environment and in a manner that supported their health and well-being. The further facilitative effect of harm reduction policies will be further discussed in following chapters.

While a minority, these participants articulated the importance of managing their addiction while engaged in the labour force. For some, maintaining sobriety through abstinence was an important factor. For others harm reduction and a flexible approach provided them with renewed access to the paid workforce. In all cases, supportive work environments played a

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critical role in assisting individuals to deal with their addiction and remain engaged in the labour force, a theme that will be explored in more depth later.

In summary, managing concurrent health issues was identified by study participants as a central vocational process and forms an important subcategory within the category of intrapersonal processes. This section summarized participants' varied experiences managing other chronic conditions, handling mental health issues, and dealing with an addiction while living and working with HIV. Negotiating these processes successfully contributed to these participants' success in labour force participation.

5.2.4 Taking Care of Self

The fourth subcategory within intrapersonal processes is taking care of self. Study participants identified self care as an essential process in maintaining successful employment. This section discusses the self care strategies that participants commonly adopted while working. These included prioritizing health, making time for self, and ensuring adequate rest. These processes contributed to the health of many participants and their subsequent success in the workplace.

5.2.4.1Prioritizing Health

As previously discussed, most participants perceived work as positively contributing to their health. Still, many also acknowledged actively working towards maintaining their health in order to continue with employment. Several participants identified a range of strategies they employed in order to manage their health. For example, participant 8, a gay male in his early fifties, highlighted the importance of focusing on his holistic health so as to be well enough to work. For him this involved the emotional, intellectual, and spiritual notions of health as well as the physical:

You know, as an example, before the medications came out a lot of people that found out they were positive turned to drinking and drugs and stuff like that, which didn't help their situation. I myself had bouts of drinking and drug abuse in that time period. So it's a complete cycle, right, and then all of a sudden you realize, you know, that you need to hold together your emotional and your intellectual and your spiritual self to work as one, and to get on this medication to live a reasonably healthy life.

Participant 27 acknowledged making health his first priority and outlined the strategies he adopted in order to stay well including ensuring adequate nutrition and exercise:

I have also decided that my health is my first priority. Everything else is second to this first priority that I have… If anything, I feel healthier now than I was, because I started being a lot more careful about what I eat, working out, supplements. So no real challenges for me, I am sorry. I guess the best strategy to stick to is to make sure I am in good health to continue to do what I am doing in the future.

Additionally, nutrition also played a key role for participant 1, who despite the added financial costs, actively maintained the best possible health in order to continue working successfully:

I probably can't emphasize this enough. Even proper eating, that is so important, whether the proper eating is your breakfast, lunch, or supper. It all affects how you're going to feel for the day. Even your supper will affect how you feel the next day. That costs a lot more money, it does. I have to spend a lot more on food now then what I was before. I can do it most of the time. Sometimes, I can't.

Several participants demonstrated that maintaining a healthy balance between work and other parts of life was an important approach to prioritizing their health. For these participants, finding that elusive balance contributed to their health and subsequent success at work. For participant 2, staying healthy involved both being aware of his limitations and finding that equilibrium between work and managing his health:

You know, your [CD4 count, white blood helper cell] numbers drop if you cannot find that balance between dealing with the disease and work. I find that really difficult. I think it's all about

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balance; it's all about organization, all about understanding the disease, and making sure that you're aware of it when you're dealing with the day to day things of your life. I am always aware that I have it. I don't want it to affect me, but I do let it, I am aware of it. So, you know, there are things like working 12 to 14 hours that might be a little too much. You need to understand that your body really cannot deal with that, because that's a little too much. So you might need to kind of balance it out.

Again, some participants revealed increasing their strength as individuals by learning from adversity and their past mistakes. Reflecting on the consequences he faced during a period of excessive work, participant 12 who had previously reported using work as an avoidance technique, cautioned as to the consequences of not finding such a balance and what he learned from this mistake:

I used to be a workaholic. That is why I got sick, because a doctor asked me to stop working at one point… but I did not listen to him. I was working like 60 hours a week. I was working, and working, and working, and he said, "You are wasting your energy, stop working, or work maybe half of the time you are working." But I did not listen to him. Also he asked me to start my medication, I did not either, because I did not have time to be thinking about medication, because I was working, working, working. I did not have time for myself to take care of myself or my health, which is why I got sick.

Thus, a key part of simultaneously prioritizing one's health and working successfully was striking the right balance between work and other life activities. Learning to establish and maintain this balance was identified by several participants as important strategies contributing to their success in the labour force.

5.2.4.2 Making Time for Self

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In addition to actively managing health and finding the right balance between work and life, many participants reported making adequate time for themselves outside of work as an additional self care strategy. For some this involved time alone to relax and for others it involved engaging with more formal social supports. Regardless, setting aside time to access support, reflect, or be alone contributed to many participants' wellness in the workplace.

Participant 23, a gay male working in a demanding management position, discussed the importance of taking time away from the stresses of work in order to look after himself and prevent burnout:

> In the evenings I have less energy to do stuff, but I have to live with that. That's why I'm going to take some time off, which I probably would have done without having HIV, because I have been doing the job for nearly 5 years, and it's a burnout job. You need to look after yourself in these types of jobs whether you've got other disabilities or not.

For participant 6, a single mother with many demands on her time, making time for self involved seeking out formal social support, a priority that she saw as central to her sense of well being and that she sometimes struggles to make happen. She recalled, "In the past year I think I've only managed to go to maybe two or three support groups. And that's a major thing, right? In my life, that's something I need to do." Participant 28 worked in a social service organization where he was constantly providing support and helping others in crisis situations. He discussed a similar need to take time away and reflect on his life and his illness:

> I need to take some time for my own knowledge around being an HIV positive individual and some self refection. I think sometimes you can be so involved and so engaged with others … that sometimes you go, oh wait, and I need to replenish my own system - right.

Additionally, for participant 19, time for self involved connecting with and nurturing more creative pursuits:

> I would still like to do some self care knowing the challenges I am going though. I also paint. I have painted 9 pictures, something I personally want to do. I wanted to become a starving artist, and go back to work at one point.

More than just time away to rest, these participants described the need for time outside of work to engage with supports, reflect on their life with HIV, and find ways to engage in other fulfilling pursuits; all activities they attributed as supporting continued engagement in the labour force

5.2.4.3 Ensuring Adequate Rest

As discussed in earlier sections, many participants reported struggling with fatigue and a lack of energy. Ensuring adequate rest was one self care strategy that participants utilized in order to fight fatigue at work, conserve their energy, and maintain good health. Reiterating the need to maintain a sense of balance in life, participant 5 described the importance of adequate sleep in ensuring a full recovery from a serious episode of illness and in maintaining her performance at work:

> I say, "One day at a time." Because my body had to recover to its natural state, as natural as it can become. But getting up to go to work in the morning was the biggest obstacle for me, and as soon as I got home I would sleep 10, 12, 16,18 hours a day. Sleep is not uncommon for me. If I get less than six hours of sleep than I feel it the next day, I feel really groggy. My body needs eight hours every day, so I strive for that.

For some, the need to ensure adequate sleep was fundamental to their continued success at work and was a planned strategy that they incorporated into their work week. Participant 31 spoke of the need for rest to ensure that he is able to meet the rigorous physical and cognitive demands of his job as a nurse:

> The evening before I start my work week, if friends want to do something, I can't. I have to be in bed by ten o clock. I have to start winding down by 8:00, so I know I can sleep by 10:00, and I have to be up by 6:00, and I have a long day to do. I have to give my energy, I have people that their life depends on me giving the right meds, and I have to be alert and responsible. So I have to be on. I don't have that sort of flexibility in terms of; yeah I would like to do this and that. No, that's work.

Consequently, many study participants were able to successfully meet the demands of work and battle their fatigue through ensuring that they received adequate rest as part of their work schedule.

In review, this section summarized the third subcategory within intrapersonal processes: taking care of self. Participants reported prioritizing health, making time for self, and ensuring adequate rest as important processes that lead to better health and wellness, and success in the workplace.

5.2.5 Recreating a Sense of Life's Purpose

As part of interviews for this study, participants described a range of concrete personal losses they attributed to HIV including health, financial, and social losses. Additionally, study participants discussed their experience of HIV as involving a loss of a sense of purpose in life. This included the pride, sense of dignity, and independence that many participants felt was taken from them by society when they were diagnosed with HIV. In contrast, work was described by many as an important process through which they could reclaim that which was lost when they were diagnosed and subsequently reinvent themselves in a new vocational role. Indeed many participants described their work as involving processes by which they were rediscovering a renewed sense of purpose in their life. This notion of engaging in work as a means to recreate

purpose in one's life is the fourth subcategory within the intrapersonal processes category and involves two properties; reinventing self, and doing meaningful work.

5.2.5.1 Reinventing Self

Participant 30, a long time survivor of the illness, described his sense of loss when diagnosed with HIV and the corresponding need he felt to reinvent himself and find a new sense of purpose. He recalled, "It's funny, I was on this path with my partner then wham; it was all over. Those plans and dreams, it just fell apart. It's like a reinventing, I felt I had to reinvent." This idea of reinventing oneself post diagnosis was also reported by participant 7 who spoke of wanting to change his career path after dealing with several life threatening health issues:

> During the recovery time I did some soul searching... and so what
> do I really want to do? I want to get back into the workforce, but I
> just don't want a job. I want something that really motivates me,
> something I have a passion for, and something that's worthy.

Participant 29, an AIDS service organization worker, also described the loss of purpose he experienced after contracting HIV, as well as that which he witnessed among his clients:

> I think that people need to be encouraged to take the lead. Because,
> a lot of times if you are sitting around there are problems with
> crystal meth, people get bored, their purpose is misdirected or
> taken from them. It's like giving people back purpose, or
> something, letting them feel valuable.

Several other participants discussed a renewed general sense of purpose and hope that they were searching for and found through vocational opportunities. For participant 14, a gay male who had recovered from a severe and disabling episode of illness, work provided a route back to life. He described this as, "A sense of usefulness, a sense of accomplishment, ya, I guess that covers it all. That and just being back to life." This was also the case for participant 13, a gay male who was working three part time jobs in education and the arts. Through these roles he reported

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gaining a better sense that he had something positive to contribute to society. As he explained, "it gives you a purpose, it gives you a goal, and it gives you something meaningful to do with your time. It also makes you feel that you're contributing something to society." Finally for participant 7, work was simply a route towards meaningful existence. He explained, "It's important for people to work… the value of work in our society is immeasurable. Right, I mean it's how we exist. I don't know. It's a capitalist rant, but you want worthwhile work."

In addition to equating work with life, participant 6 described how employment provided a powerful route for confronting his pain and finding purpose. In addition to dealing with HIV, he also battled an addiction to crystal meth. In this case he felt that a loss of purpose contributed to his addiction and the hope of returning to work provided him with the motivation to enter recovery and eventually improve his life circumstances:

> I believe it's important to dream, to have hope. And I had to have hope… that was the one thing that the union gave me that I didn't have when I was lost in addiction. I had lost hope, I didn't think that I would ever work again, so what reason did I ever have to stop? In fact I was in so much pain that the only thing to help the pain was to continue using. When the union said there was a chance that I might be able to go back, even though it was a year and a half before I actually went, the hope that I could go back was enough to make me stop. So having hope that you will recover, that you will have a life, is incredibly important, and it is key to recovery.

Participant 2, a young gay man diagnosed with HIV only 2 years ago described gaining a new perspective on life, a clearer focus on his vocational and employment goals, and renewed hope that he could realize his dreams; successes that he attributed to his experiences living with HIV:

> Becoming HIV positive kind of changed my life in the positive. I definitely tell people, and people look at me weirdly by saying that becoming HIV positive was like the best thing that could ever have happened to me. It changed my life. I realized life has so much more potential and, you know, you take life for granted a little bit

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before. And now I don't take life for granted. I think life is so
much better, more beneficial. It's made life so much better… it's
just helped me, and put me in a more positive, go-getting, go-getter
kind of environment and feeling.

Therefore this notion of reinventing oneself post diagnosis was an important theme within the

broader subcategory of recreating life's purpose and one experienced by many participants.

5.2.5.2 Doing Meaningful Work

For several participants reinventing self and recreating purpose in life was connected to

the idea of doing work they find meaningful. Several participants reported gaining this sense of

purpose by engaging in jobs where they were helping other people. For participant 7, meaningful

work involved helping others in his job as a street outreach worker. Although he reported being

triggered to revisit painful experiences on the job, this was a process through which he also

gained a sense of growth and purpose:

It's just actually being with somebody going through some pain,
and being open for sharing that pain. And there doesn't always
have to be a great outcome. You know, just going through that
process even though it's painful at times. People grow through
pain. I mean, I have too. But certainly not near as much pain as
what some of our clients have been through. It fortifies you.

Participant 18, also a street outreach worker, reported similar feelings. He described finding

purpose through working to prevent others from experiencing some of the things he had been

through in the past. He explained, "I have been there before. And testing positive, I guess I

wouldn't want anyone else to have that happen. So, I care for other people like Trans people, and

gay people, and Native People." In both cases, these participants were recreating a sense of

purpose for themselves through their work. For others, this involved reaffirming or rebuilding

identities as workers and incorporating their experiences as people living with HIV into a new

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vocational purpose. Participant 30 spoke of how he rebuilt a sense of identity through teaching

and caring for others:

> Yes definitely it gives me an identity…I feel that it's important to
> me to have some sort of identity, and seeing my self worth, and
> participating. I have younger students. I have a mixture of men and
> woman. It's nice; I feel I am teaching them something they can
> spread to other people. The type of work I am teaching is very
> nurturing, therapeutic, caring, not just physically, but also
> emotionally. I teach and talk often about nurturing people, caring
> for people.

This process was also described by participant 9 who reported drawing upon his own experiences

and learning to assist others. After dealing with his own addiction issues, participant 9 retrained

as a support services worker where he too found purpose in helping other people:

> Well yes of course I want to survive, and I want to have something
> when 65 comes, because I don't have anything yet. But it is also
> important for me to be able to do a job I believe in and I enjoy
> doing. This job for sure is that… I think this is the first counselling
> job I actually feel I am doing something to help the clients that are
> participants. In other jobs the bologna from the top gets in the way
> of being able to help the clients. I hated being stifled that way.

This was not just the case for those participants working in the health and social services

sectors. Several participants working in the private sector and in transportation also reported

gaining a sense of purpose through their work. Participant 3, working part time as a bus driver,

described how his work provided him with a chance to recreate a sense of purpose after

recovering from a serious episode of mental illness:

> Feeling better about myself, feeling like I'm a part of society.
> Feeling like I'm contributing something to society, and I'm doing
> something that's worthwhile, something that's looked upon. I mean
> the kids rely on me every morning, and to drop them off every
> night safely. Just the well-being, feeling useful.

Additionally, participant 5 spoke of the satisfaction and purpose she received from her job in financial services. She explained, "the mortgage is the biggest investment one makes in their life so if you summarize it in layman's terms people aren't so threatened by it. I just appreciate being able to give people their details." Thus work provided the opportunity for these participants to revisit their hopes and dreams, reconnect with their values, and recreate a sense of purpose for themselves. This process is summarized by participant 29:

> There is no more of that nagging question in my head like, you know, what are you doing? And now it's not like I wasn't doing stuff before, but there is this work ethic, and wanting to know that you are being involved in something meaningful and engaged.

For some participants this need for a sense of purpose was not just isolated to the work world. It was a process that they acknowledged as important in other life domains and something they would continue to pursue elsewhere regardless of their vocational opportunities. Participant 31 described how his need for purpose existed independent of his professional identity:

> Life does not end just because I cannot work. It just changes. You find your purpose somewhere else. I think it's important to remember that, because I think so many people define themselves by their profession, and it's so important not to. I think that's one piece, but just because I am not working does not mean I don't have a whole lot of skills and things to offer. I have gained because I have worked.

Participant 30 reiterated this and acknowledged a diversity of activities (including work) through which he found this sense of purpose following his HIV diagnosis:

> I got involved with interesting volunteer work, interesting activist work; I even worked on research studies… I wanted to reinvent myself, and feel like I am part of this community. For my own survival, [and] my own well being it's important for me to do some sort of work that's meaningful to me.

Thus, many participants engaged in work not just as a means of financial survival but also as a process for recreating purpose in their life following the losses they associated with being diagnosed with HIV. Reinventing self and recreating a sense of purpose are closely related to other categories particularly developing resilience and the GIPA principles and will be further discussed and integrated in coming chapters.

5.2.6 Thinking about the Future

As discussed earlier, uncertainty regarding the effectiveness of medication and disease progression is an ongoing concern, one that had a direct impact on participants' vocational goals and future plans. Managing this uncertainty while preparing themselves for the future was an important process reported by many study participants and is the final subcategory in the intrapersonal processes category. Participants reported a variety of responses to uncertainty. These responses ranged from fear and worry to actively strategizing for the future. Regardless of the response most participants were actively engaged in a process of contemplating their future. This process was comprised of several properties related to how participants manage their hopes and goals for the future; dealing with uncertainty, compromising one's goals, and pursuing vocational goals.

5.2.6.1 Dealing with Uncertainty

Naturally, the impact of living with HIV and related uncertainty had a serious negative impact on many participants' aspirations and hopes. When contemplating their futures some participants expressed extreme fear and pessimism. This seemed to be especially the case both for women and long-term survivors of the illness. In some cases, these negative feelings were due to a long history with HIV that involved experiences of illness and loss. Participant 31, a nurse and a long time survivor of HIV, spoke of being unsure about his future in the profession:

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> It always kind of weighs on you. I saw my first partner die. I always kind of feel that I don't know how long I am going to be able to work for. It's one of the main things that kind of weighs on my whole life. I am not quite sure how long I will be able to work for… I am 43 now, I will qualify for an unreduced pension at 58, can I do another 15 years? I don't know. Am I going to have to do LTD [long-term disability]?

This fear and concern was reiterated by participant 12, a gay man who had also been living with the illness for many years. As part of managing uncertainty, he reported suspending his hopes for the future, at least temporarily:

> Looking to my future? It is like I stopped looking for my future, because I am afraid what will happen. This fear stopped my brain, it is a life time goal I am going through. That is why I need some time to do my therapy, and go through all the stuff, then maybe one month or two months I can come back and check for a career.

Fear that the illness will once again be life threatening was expressed by participant 20, another long time survivor living with HIV since 1994. He stated, "All of a sudden you are handing me the world, what happens if I screw up? Don't worry about it? Suppose my condition comes back"? For these three individuals who have been managing the illness since before the advent of effective HIV medication, physical survival was more a priority than was planning for their future careers. Hence dealing with uncertainty was a serious challenge faced by many participants and impacted their vocational hopes and aspirations for the future.

5.2.6.2 Compromising One's Goals

For other participants, living with HIV meant that they needed to compromise important career goals and aspirations. Participant 23, a professional in the private sector, described abandoning his ambitions at work in order to focus on self care:

> I don't want more responsibility, and I was at that point where I probably wouldn't want it anymore anyways. But it's hard to say, because I could have been manager if I wanted to, but definitely

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> not now. I'm more focused on things for myself, what can I do that
> will improve my own self knowledge and self worth for me?

Similar concerns were expressed by some women in the study. Although less likely to have been

living long-term with HIV, these women carried a greater burden as care givers for children and

other family members; responsibilities that combined with HIV to limit their career aspirations.

Of the seven participants who described compromising on their future career goals, the majority

were women. Participant 6 spoke of dealing with these limitations:

> And so this thing about, "Oh, you can and you can get it, you can
> do whatever you want". With my experience it doesn't work if
> you have HIV. You know, you could push and you strive, and one
> day your status will creep up on you when you least expect it. And
> it just whacks out everything you've worked hard for. Unless, if
> you're one of the lucky people, that you are in a different place in
> your life, and it doesn't matter if people know your status. Those
> are the lucky people. But, you know, for some people like me who
> is a mother, I am not the only one I need to think about. So, very
> few people that I know are having their dream jobs. It's a
> compromise and at the end of the day; you have responsibilities.

Participant 5, a single mother, described holding herself back from training opportunities out of

fear of failing due to her illness:

> I don't know what I'm capable of doing, to do all those courses
> along the way, although they are offered through work, will I
> succeed? Will it be something that will stifle me at all in the course
> of the study? Yeah, I just take everything one day at a time. I'd
> love to have aspirations to go up higher, but I'm just inching
> towards that.

Additionally, participant 4 described her desire to start a new career in Canada by working with

children; an ambition she decided to forego due to a variety of barriers including recent

immigration, financial circumstances, and fears regarding her HIV status:

> I would be really interested in doing something with children, but
> it won't be easy. It would take two years, and it's a long time. I
> don't want to wait two years to start a job, and then when you take

> the job you have to fill out the forms and other things to make sure
> you're safe for children.

While compromising one's goals was not restricted to female participants, a combination of barriers meant that the women in the study were more financially vulnerable and less able to take risks. In particular, participant six expressed a great deal of ambiguity and pessimism about her future. A single mother, she was feeling both financially and emotionally vulnerable; expressing caution about planning for her retirement, feeling as though she can't get ahead no matter how hard she works, and even questioning her will to live to 65:

> Who cares if I live to 65 to be perfectly honest? I don't care, the
> world is so unstable at this point in time be my guess as to
> whatever's going to happen, but I will just keep working until I
> can't work and then see what happens.

Despite currently being successful at work, other participants also felt ambiguous about their future prospects and expressed a sense of resignation. Participants commonly spoke of managing this uncertainty by just moving forward and hoping for the best while suspending any firm hope for the future. Participant 16, a young gay man, discussed how he manages:

> To be honest, I'm cruising. I'm just in cruise control, just moving
> forward. I'm kind of taking it, I wouldn't say one day at a time, but
> I take one year at a time. I don't know what I'm going to be doing,
> but, you know, hopefully I can keep the energy up

This sense of taking it one day at a time was also described by participant 5 who stated succinctly, "I just keep a low down profile and just keep going one day at a time." Thus for this participant and many others compromising one's vocational goals was a necessary and appropriate response to the diversity of personal and contextual challenges they faced while living with HIV and working.

<u>5.2.6.3 Pursuing Vocational Goals</u>

In contrast to those who were suspending or compromising their career goals, some participants were more optimistic and were actively engaged in the process of planning for their future. These participants described a range of plans they were working towards as part of realizing their career ambitions. Several participants who were working part time were hopeful that they would be promoted to full time positions or positions with increased responsibility. When contemplating his future plans, participant 9 spoke of hopefully expanding his role as a peer researcher into a full time position:

> I would like to stay gainfully employed, hopefully full time, when
> things open up, and I am counting on them doing that. Being
> positive, and remaining optimistic that I could keep working on
> this program… there is a big potential for growth.

This was also the case for participant 18 who had aspirations of transitioning from his roles as a part time street outreach worker to a more stable and professional position with his current employer:

> Give me a few more years, maybe they [employer] will trust me
> with a full time job, an administrative desk job where I can literally
> refer people, I don't know, what do we call it, a support worker?
> Where I help people to go to their doctor, or what I am doing now
> but on a more professional level. A good nine to five job.

When discussing their future plans, several participants revealed strong career ambitions and motivation; personal qualities that had already contributed to their success in the workplace despite HIV associated barriers. Participant 19, a quality control professional, spoke of taking on more responsibility at work and of becoming a manager someday. He felt confident that his current success at work would translate into more responsibility and being considered for leadership roles:

I am getting more and more responsibilities from my colleagues
and my bosses. I am getting more involved with projects and
decision making. According to my boss and his evaluation, he says
I am the right person to lead processes. It won't happen tomorrow
or the next day, but they see it in progress. So I have to prove that I
am the right person to be picked from among the other guys. I see
more duties on my plate daily; it's a good sign for me. Hopefully I
will go forward with this, or any other organization, to get in to
more manager position, of course improve then to be a leader in
my field.

Participant 28, an AIDS service organization worker, described his hopes that he could grow into

a position with more responsibility within his current agency:

I would be very much interested in being in a director position in
my organization because quite often I feel like I am already
operating at that level… I am doing my quarterly reports, and the
narrative, and other departments. It is shared between the director
and the coordinator, so in that regard I look forward to being a
director or also being human recourses manager.

As discussed previously, many participants welcomed opportunities for learning and

growth and reported actively seeking out vocational training and education as a means to

achieving a better future for themselves and their families. In achieving this, a desire to learn

new skills and to educate themselves for future vocational roles was commonly reported by

several participants. Participant 4, a recent immigrant facing multiple vocational barriers,

described how she embraced language instruction and education as part of her efforts at

improving her job prospects in a new country:

I was a student. I went from one school to another one when I
came here. I took French classes because I didn't know where to
take courses… Now I want to continue with my English classes,
and then add some other subjects. Maybe get into another program
in college, and then get a job.

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For some, education was a strategy in navigating a difficult transition to a new career. Participant 17, a counselor, spoke of the need to balance work and school in order to maintain an income and create a desirable vocational future for himself:

> When I came back to work, I worked for three years at a job that I ultimately did not like. So I left that job, went back to school, finished off my university degree, did a post degree diploma in counselling. So the security aspect comes in that I had income while I was going back to school.

The idea of changing career paths was not uncommon as several participants reported being in the midst of a career change or wanting to change careers in the future. For some this involved seeking careers within AIDS service organizations, opportunities they perceived as providing meaningful work and allowing them to utilize their experiences living with HIV in order to help others. Participant 12, a gay male, described his desire to change careers after ten years in the hospitality sector:

> That is why I came here, because I wanted to change careers. I wanted to do something else like counselling, peer counselling, or doing something for people with HIV with all of my experiences. I have been training and doing that.

Participant 11, a gay male studying part time, described how pursuing educational opportunities contributed to his success in the workplace and helped facilitate a change in careers from marketing to AIDS support work:

> Keeping myself current, not allowing myself to sit around to deteriorate or allow my skills to go out of date. All of those things have led to my continuing success in being able to find employment, even given changing from one type of work from marketing in media to working in AIDS.

For others, a change in career path meant realizing other dreams. Participant 26 described his

desire to leave his job in social services after 20 years to start up his own bed and breakfast, a

change he attributed to the impact of his illness:

> After 20 years of that, I just thought I needed a change. I worked a
> lot of evenings and weekends, it wasn't stressful it was a good
> stress. I just thought I needed a break… So I just wanted to
> continue working, something with people just not social services
> so much anymore … so I did a bed and breakfast, we had a 5
> bedroom and 3 bathroom house.

As part of discussing his future plans, participant 8 also indicated a desire to change careers and

start his own business:

> I'll start my own business. Actually I'm thinking of moving out of
> the city, moving up north… and maybe starting a hunting camp or
> retreat or something up there. Yeah, I need a change, and I think
> now is a good time.

Hence many participants reported actively thinking about their futures which was an

important process involved in managing their vocational goals. As part of this subcategory

participants reported a range of feelings and thoughts including pessimism, ambiguity and

optimism. Several participants were strategizing to achieve increased responsibility in their

current employment and positions that could better meet their career goals.

To conclude, this section involved a description of the first major category in the

framework, intrapersonal processes. Study participants reported a variety of processes related to

health and personal psychology that they perceived as important in contributing to their success

in the labour force. These were managing episodic illness, experiencing concurrent health issues,

taking care of self, finding/rediscovering a sense of life's purpose, and planning for the future.

5.3 Chapter Summary

This chapter described a main area of psychosocial process characterizing participants' successful experiences in the labour force, key elements of this conceptual framework. This category was intrapersonal processes, those primarily related to an individual's health, knowledge, attitudes, and skills that influence success in the labour force. Chapter Six will continue with a description of the study findings with a focus on interpersonal processes.

CHAPTER SIX: THE INTERPERSONAL PROCESSES

6.1 Introduction

As indicated in chapter five, within the ecological framework, two key areas of psychosocial process characterize participants' successful experiences in the labour force (see fig. 5.1). As discussed in Chapter 5, the first category was intrapersonal processes; those primarily related to an individual's health, knowledge, attitudes, and skills that influence success in the labour force (McLeroy et al., 1988). This chapter will discuss interpersonal processes, the second major category in the framework. Interpersonal processes, are relational processes primarily attributed to social networks, relationships, and interpersonal dynamics that influence success in the labour force (Sallis et al., 2008). Within this key category are a variety of related subcategories. This chapter describes the properties and dimensions of this category in detail.

6.2 Interpersonal Processes

This category is comprised of five interrelated subcategories, each of which defines and describes a set of interpersonal processes that participants described as essential to working successfully. These subcategories – developing resilience, advocating for self, managing disclosure, managing relationships, and employing workplace skills and coping strategies – are described in detail in the following section.

6.2.1 Developing Resilience

As discussed in earlier sections, many participants described facing numerous HIV related challenges that disturbed their existing self-identity and required them to reconstruct a sense of meaning and purpose. Apparent throughout several categories and subcategories of this framework is a degree of cognitive and reflective capacity that allowed many participants to appraise situations accurately and to figure out adaptive strategies for dealing with difficulties.

Several participants discussed the emotional and psychological foundations of this process as well as how they developed this capacity within caring and supportive relationships. For these participants, work was a key protective factor reinforcing their role as active agents in their own survival and growth and providing opportunities for rebound and resolution in the face of serious challenges. As part of their success at work, these participants had developed or were engaged in developing resilience in the face of various vocational and life challenges. Defined as an interpersonal construct involving successful adaptation to negative life events, this resilience existed on a continuum and was both a product of and a contributor to many participants' success in the workplace (Emlet, Tozay, & Raveis, 2010).

Several participants reinforced a notion of resilience as being the ability to recover from illness and loss. Participant 21, a gay man and a newcomer to Canada, spoke of his journey recovering from the shock and trauma of his HIV diagnosis and how he found the determination to continue living:

> When I was diagnosed, all my space and my life was really living in grey, it was really bad. Not having any family member with me or having someone to rely on, I was feeling desperate. I was feeling like I was very close to doing something crazy. Because I had this in my mind; if I ever got HIV I will just kill myself. Then after the diagnosis I was like, okay, I have two options; should I go just finish with my life? Or see what one more day is like and just continue on fighting for this?

Participant 29, a long time survivor, also spoke about recovering from illness and the links between renewed health, social support, and a developing sense of strength and resilience:

> I started feeling better. After a few years I actually started feeling better. It was almost like a cloud was slowly being lifted off me. I felt stronger. It's funny; adversity can make you stronger even though I don't recommend it. I don't want it, but when I look back on my life it has always been a time of adversity that has made me stronger.

Participant 5 spoke about bouncing back and moving forward with a renewed sense of hope and determination after dealing with a diverse set of health and social challenges including HIV, Hepatitis C, addiction, and homelessness:

> *Participant:* Resilience also means something bad happens because you got to have to bounce back, right?
>
> *Interviewer:* How do you define resilience for yourself?
>
> *Participant*: Being able to bounce back… so resilience would involve change. It is one thing to bounce back, but if you bounce back from the same damn situation, that's not resilience, it is insanity. You need to have resiliency with a change to a positive outcome.

Additionally, participant 14 described how he rebounded from illness and rediscovered the sense of agency and determination he had grown up with; personal capacities that served him well in returning to and sustaining successful employment:

> I was an individual that never phoned in sick to work… When I wanted something, I got it, no matter what, at any cost. When I was diagnosed, a couple months later, I just, I would call in sick. I was complete, completely opposite…. I think because I was so determined to get back to work, and I am one of those people that - don't tell me I can't. And I just got the ball rolling. And it made me determined to do it. So it didn't take me away from not doing it or discourage me, it encouraged me. And now I'm back.

Participant 6 described recovering from another type of loss, the death of a family member. She recalled, "I lost my husband …in my early twenties with 2 children. I've had to leave my country to come and settle here. I've always been the breadwinner; I don't give myself any other alternative."

For many participants, developing resilience also involved having a sense of personal agency. Study participants described this using terms such as, "being determined", "keeping the fire going", "being driven", and "showing persistence". For example, participant 3 described

becoming driven to pursue his vocational goals despite dealing with HIV and concurrent mental

health issues:

> I've had points in my life where I've had a lack of self-confidence
> or a lack of drive, I guess you could say, or the motivation to do
> certain things. When it all came down to it, and I knew I needed to
> do something, I would do it. I mean I moved to [a city] at the end
> of 2005, and my mental status was stable at that point, and within a
> month and a half I had enrolled myself in community college, and
> I had part-time work… and I had so much drive. When I look
> back, I went and did all the appointments that I needed to get the
> ball rolling, to get the funding for college, and I did it all myself,
> and I don't know what was driving me. Sometimes I look back, and
> I wonder what was driving me, but I did it.

Several participants confirmed this sense of determination as a protective factor that was

instrumental in concurrently dealing with HIV and sustaining employment. Participant 6

described this determination as a "fire" that helps keep her going:

> *Participant:* I think, for me, it's just a, it's just a fire. You know,
> and you just have to keep fueling it. It's a fire, and if it burns out,
> you know, the fire just takes over. You just have to keep going,
> and it's hard, it's hard. Sometimes it's better to just let go, cause
> it's easier.
>
> *Interviewer:* It doesn't sound like you've done that though.
>
> *Participant:* I have! I have. I have, and, you know, you just wake
> up one day, and it's not a choice.

Participant 8 described similar ideas, emphasizing the importance of persistence in achieving his

vocational goals:

> But I have a personality similar to that. If I don't get it once, I
> keep trying, and keep trying, I just keep going. I am so persistent.
> When I set my eyes on something I just keep trying that's all.

Finally, participant 7, a heterosexual male working in the nonprofit sector, spoke about the

importance of the anger and determination that lay beneath his sense of personal agency:

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> You know I'm still a little angry after my cancer. Like, I really
> didn't embrace any spiritual path. For me it was a competition....
> nothing was going to get in my way and despite the mortality rate
> of esophageal cancer I was going to be...I just had it, you know. I
> wasn't relying on prayer and meditation. I don't know if that's the
> most healthy way to go about it. My doctor said, "It worked. So,
> who cares"?

Several participants described becoming stronger and more resilient through reflection
and learning from earlier difficult experiences and applying this in their current situation.
Participant 9 described the learning he took from a long history of dealing with an addiction and
acknowledged that being open about his mistakes helped him move forward with strength:

> I am not going to be perfect, that is what I always wanted to be of
> course, and acknowledging when I make a mistake and when to
> reach out for some help and guidance and being okay with doing
> that as well. I think that it is important to acknowledge our frailties.

Participant 7 also attributed his resilience in dealing with HIV to earlier difficult experiences in
life suggesting that, "The word resilience really, I mean my experiences, were a conditioning
more than anything else." Additionally, participant 8 described how his cumulative experiences
dealing with HIV and associated barriers better prepared him for the decisions and challenges he
now faces:

> Because now I've gained the experience that when I come upon a
> situation I know exactly what course I should take to deal with that
> situation. It's all the learning curve, right. When you're first
> dropped into this, and you don't have any experience then you
> don't know the right choice. You can go back and say, "Listen,
> you know what, that is a stupid decision I made yesterday about
> that, or about the dog or about the car or anything in my life. Was
> that a well rounded decision? Did I think it through, did I research
> it? Is that the way I want to go?" So, that's how your mind works.
> After you get the confidence of running through this once, then
> you know.

The ability to learn from earlier experiences and draw upon this knowledge when dealing with

HIV and vocational obstacles was an important factor for many participants as they developed a

sense of resilience. This was the case for participant 9, a gay male who found his way back to

employment after struggling with an addiction for many years, an experience that prepared him

to be successful in his current position as a peer researcher:

> I would go on these messy things, and lose the job, I was in sales
> before, but I would always get back up. My focus was always to
> get the job, then I would fall apart again. I finally realized there is
> some stuff going on that you have to look at… We say "If you
> keep doing what you did you are always going to get what you
> got." So being HIV positive enabled me to go on to ODSP, that
> enabled me to take the time to do the personal work in AA
> [alcoholics anonymous], just clearing stuff up and getting myself
> clear so I would be able to come in to a work situation and not be
> pulled away by my own unresolved issues.

Certainly not all participants described a sense of resilience in similar terms indicating that the

degree of resilience participants displayed exists on a continuum. Participant 5, a single mother,

was often ambiguous and pessimistic in her narratives. Often dealing with depression and self

doubt, she nevertheless also reported some degree of gaining strength and learning to cope as she

moved forward and faced challenges:

> At first, to be perfectly honest, even during my seroconversion and
> getting sick, clients would affect me so bad. But, I don't know,
> over the years now I brush it off. Everybody's human, they have
> bad days, just deal with the issue, move forward, turn the page.

Many study participants reported drawing strength and resilience from friends, peers and

other informal social supports. For these individuals, resilience was a relational dynamic located

within mutually reinforcing and caring relationships. Participant 6, a women working within an

AIDS service organization, articulated how her peers and her children both stimulated and

witnessed her developing sense of resilience:

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>I think the fact that I am easily approachable and I like being surrounded by people; that has really helped me. So I haven't isolated myself, which is something that I struggled with the first 2 years of my diagnosis. And for me, my number one priority is that I am a mother to teenage daughters. And it's really important for them to see me fall and get up constantly. That's like key for me, cause they are, I'm bringing up women, right.

Participant 29 also acknowledged the role that others played in helping him develop resilience. He remarked, "Maybe that's my personality, and I had help, I had a caring doctor, and there are nice people here at the hospital. There were friends, caring people that helped me along the way." Additionally, participant 31 described how being open about his HIV status helped connect him to the supports in his life and subsequently develop the strength to learn from his mistakes:

>I had a lot of support, but … I think that coming out is a process that can make you stronger too. You have to believe that you are human, that you are not perfect, and that your imperfections actually make you stronger. I certainly made mistakes in that process, but that's part of being human.

These participants supported the notion of resilience as rooted within the dynamics of interpersonal relationships. Drawing support from and managing relationships were important processes involved in working successfully and will be discussed in more detail in forthcoming sections.

As a final point to this section it is important to note that several participants attributed their sense of developing resilience to their participation in the labour force, suggesting a mutually reinforcing relationship between work and resilience. For some participants, employment allowed them to counter the effect that HIV has over their life and identify. For example participant 7, an outreach worker, remarked how he believes employment contributes to both his health and his developing resilience. He suggested that for him, "Being active and

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working prevents illness and it builds in that resiliency." Participant 31 reiterated this, connecting his increased confidence and resilience with his professional growth. He reported how this sense of resilience was connected to a renewed sense of purpose at work and an ability to better empathize with and provide service to his patients:

> When I had to go back to work I had a lot of shame and guilt
> around the addiction. I needed a lot of support around that, but I
> also had to come back in terms of just telling myself that I am
> human, I do make mistakes. The fact that I make mistakes and I
> am human actually makes me stronger; it makes me a better nurse,
> because I can help. The people that I help make mistakes, and a lot
> of them have made humongous mistakes in their lives and don't
> know quite what to do. I can relate. I know what they are going
> through. I made a huge mistake, and have made many mistakes in
> my life, and I have built it back up. I believe in recovery.

In summary, several participants described developing resilience as an important interpersonal process connected to their experiences of working successfully. Specifically, these individuals described recovering from illness and loss, a determination to achieve their goals, an ability to learn from earlier experiences, and actively drawing upon support from family and friends; all key properties involved in developing resilience. A mutually reinforcing relationship between work and resilience helped many participants to feel empowered and able to counter the effects that the disease had over their lives.

6.2.2 Advocating for Self

In addition to reporting determination and resilience, many study participants described needing to advocate on their own behalf in order to successfully manage a variety of systems. Advocating for self is a related subcategory within the category of interpersonal processes. Collectively, self advocacy skills are a mechanism by which people living with HIV can influence interpersonal, institutional, community, and public policy environments. These

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behaviours and abilities involved being informed of one's rights, speaking out on one's own

behalf, and challenging systems that are unsupportive or discriminatory. Several participants

described developing these skills over time as they faced various challenges and obstacles related

to living and working with HIV. These strengths were seen by many participants as being

instrumental in their success in the workplace.

Within an employment context, several participants identified the importance of self

advocacy skills as tools for addressing a range of issues including abuse, discrimination, and

stigma. Participant 8, a financial services employee, said simply, "The only way you're going to

win, it's a proven history … If you do not fight for your rights you will get nothing. That's the

absolute truth of it." He then went on to compare his ability to advocate for himself with those he

had seen fail in similar pursuits:

> There's no question why people fall through the cracks. Number
> one, they're not educated or know what their rights are; number
> two, they're not strong enough to try and stay on board to fight for
> themselves. In a way, not only are you fighting for your life,
> you're fighting to keep yourself healthy, and to hold an income
> down. So now not only do you have your business life, you've got
> other things that you must attend to if you want to move ahead. So
> you have to have a strong personality.

Other participants described using self advocacy skills to defend themselves against abusive and

exploitive employers. Participant 1, a federal civil servant, described the measures he took to

advocate for himself when dealing with abuse from a supervisor:

> I ended up having to go on leave because this person just drove me
> to no end. So I just made a couple of phone calls to Ottawa. What
> will happen when I go into a really, really deep depression: I don't
> know what it was but that's when I'll take action... I go where I
> know something will get done. They had someone go in, and all
> the staff in the office were interviewed. After the interviews, they
> had to fill out a questionnaire. This manager I was referring to,
> they were removed.

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Participant 4, a recent immigrant working in a physically demanding job as a cleaner, also

reported having to confront an abusive employer:

> She doesn't have good relationships with her workers and when I
> saw she would do something like that for me I wasn't willing to
> take it because the other ladies that were working with us they
> weren't aware of their rights. But for me some of the things she
> was trying to do; I was like you don't have the right to do this.
> Because sometime we would come to work and we would have
> five things to do and she would say you have to do this again and I
> would say in what time and she would say you don't have to say
> anything and I said I have to do something.

Participant 6, a women working in an AIDS service organization, also acknowledged the

importance of knowing her rights under the law as a necessary aspect of advocating for herself,

and securing needed accommodation from her employer:

> And, uh, I think another strength of mine is that I've taken time to
> know what my rights are, not only as a PHA [person living with
> HIV] ,but as somebody who is employed. The employment
> standards, I know what that is, so I know what I can ask for. For
> instance, I know the accommodations that I can ask for to work as
> a person living with HIV. So, when I ask, I am not asking for
> favours. And I think that's where the difference is.

Additionally, participant 7, a street outreach worker, described his efforts in helping his clients

develop the same self advocacy skills that he attributed to his own vocational success. He

explained, "I try and get people to self advocate more … trying to light that fire, that little fire. I

feel that's part of my job. In the HIV community, we're pretty good at self advocating."

Some participants described developing advocacy skills as part of dealing with other life

challenges as gay men, women, or racialized minorities. In these cases, overt discrimination in

the workplace demanded that they utilize these skills to protect themselves. Participant 23, a

male who recently disclosed his homosexuality at work, described how he managed this process:

I am quite capable of standing up for my rights because I wouldn't allow someone to discriminate against me in that way. The same way that if I'm gay and being shut out of the boys club. I've traditionally worked in boys club type environments, so I haven't necessarily divulged anything about my personal life, and I don't socialize with a lot of the people I work with because of that very factor. If I ever felt that I was being discriminated against I wouldn't have a problem with dealing with that directly, and I work with lots of athletic types, they are all sporting physio types, and my boss is one of them, and I haven't had anything negative from him at all.

Participant 15, a recent immigrant described how he struggled to stand up to racist co-workers in his job in a food processing plant:

They discriminate openly, the immigrants, they despise them, the fucking immigrants. Simple as that. I have a problem there, but not HIV; the color of my skin… one machine was broken, he told me, "Fuck you, fucking immigrant." I put it in writing, and it was not the first time. I went to see the manager, and said I had a complaint in writing. They follow the proceedings, the guys after that they did not speak to me again. They told them if you tell him something else you are out.

For these participants, successfully confronting stigma and discrimination were important processes that contributed to their success in the workplace.

For several study participants, self advocacy was also a necessary skill in attempting to access medication and in dealing with medical benefits providers. Participant 9 reported having to use these skills to advocate for access to critical, life saving medications. He described in detail how, early in the epidemic, he advocated within his workplace for access to newly available medications and for the company to cover these costs:

And it's funny how that worked out actually because that shitty job saved my life. What happened was that the medication came out, and their corporate head office moved out to [city]. And the medication came out, and it was extremely expensive, and I actually went to the vice-president… and said, "Listen, I need this medication. And, oh, by the way, I'm HIV positive and I'd really

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> like to live if you don't mind signing off on this medication
> because I'm told this will help me."

Additionally, many participants have described needing to advocate for themselves within public medication benefits programs such as the Trillium program in Ontario and with income maintenance programs. Participant 6 reported struggling to ensure that her medication would be covered by her public benefits provider:

> So I found myself paying shortfalls of $600, and $800 a month
> right, and then I had to literally fight, really had to make ODSP
> [Ontario Disability Support Program] recognize that I needed to go
> back on ODSP for my meds.

Participant 7 outlined how his ability to advocate on his own behalf assisted him in negotiating with his benefits provider:

> What they promise and what they represent is certainly not what
> they provided. I tried to take some courses and it's not covered. So
> how does anybody get ahead here? And you know I'm fairly
> assertive and forthright, pretty demonstrative about what I want to
> do, and how I'm feeling. But a lot of people I see in the ODSP
> [Ontario Disability Support Program] office, a lot of them feel
> powerless. I felt a real power shift in that culture, and it's toxic for
> people who aren't empowered enough, or who aren't confident
> enough or assertive enough for making self advocacy.

Further issues associated with income maintenance systems and other benefits providers will be discussed in detail in following sections. Nonetheless, many participants described self advocacy skills in a variety of settings as essential to their vocational success.

6.2.3 Managing Disclosure

Issues related to employment and disclosure of HIV were a critical concern for people living with HIV involved in this study. As anticipated, study participants detailed a broad array of experiences and challenges related to disclosing their HIV status at work. As such, managing disclosure is an important subcategory and an essential interpersonal process that participants

reported engaging in as part of their vocational experiences. Generally, study participants described utilizing a broad range of strategies when managing disclosure in the workplace. Narratives revealed a continuum of approaches ranging from concealing the illness to selectively disclosing to trusted peers and co-workers to a more public form of disclosure. While all participants discussed needing to manage disease disclosure as part of working successfully, they were evenly divided along this continuum with no one approach being more dominant than others. This suggests that participants considered a variety of complex personal and environmental factors when deciding which strategy was likely to be successful given their unique vocational situation.

6.2.3.1 Concealing the Illness

As a primary attempt to manage and control disclosure of their HIV status, many participants discussed actively concealing their disease from others in the workplace. These participants described it as a self protective mechanism, a response to the multiple levels of stigma and discrimination they felt they would face were they to disclose, and a way to protect against further losses as a result of the disease. For some, the idea of disclosing their HIV status at work was simply out of the question. This was certainly the case for participant 8, a full time employee in the financial services sector who had a history of litigation with a variety of companies, experiences that had eroded his sense of trust in all employers:

> The thing that's the most important to me is to never divulge anything; never... it's never in your best interest to divulge anything in the workforce. You just don't do that- okay. What you do is, you get into the company, you do a good job, you get your benefits, and then later down the road, if need be, you can get back to that. But you never do that because you won't get anywhere in corporate Canada. That's the facts... keep your baggage to yourself.

Participant 2, working part time in the transportation sector also shared his reluctance to disclose his status to anyone at work. He explained, "As far as my employment goes, they are not aware of my health status, and I really don't want to share that with them." Participant 5 felt that her health status was a private affair, not information to be shared at work:

> It's my personal business. It's bad enough when they swipe my
> health card, I think right away something comes up and tells them
> my status. I'll just keep to myself, and mind my own business, just
> deal with the issue at hand, right.

This was reiterated by participant 27 who felt strongly that disclosure of his HIV status was not relevant in a vocational environment:

> I think you have to be crazy to tell your employer. If I was an
> employer and somebody came to tell me I would say, "Why are
> you telling me this? Who cares? This is not something that pertains
> to your work."

In addition to generally guarding their privacy, several study participants reported concealing their status due to fear of negative reactions on the part of their employers and co-workers. For instance participant 16, a waiter, reported not disclosing his status at work for fear of stigmatizing reactions from co-workers if that information was shared:

> We have a staff of over 80. It's one of those things, that if it got out
> it would just be immediately disastrous for me. I'm sure over a
> time it would be OK. But when you're in a corporate restaurant
> and there is a staff of 80, and then there's other locations in town,
> it's like a gossip mill. It's just one of those things that I wouldn't
> talk about, you know.

Purposely concealing the illness out of fear of discrimination was commonly reported. For example participant 24, a married, mother of two teenagers, discussed concealing her illness in order to prevent the stigma so often associated with HIV:

> We haven't told many people, and that's the other thing. I hear
> about these terrible stories from some of the people, and I think

maybe I shouldn't tell anybody. I go to stigma workshops, and I
just think "oh my God". It is kind of frightening to hear some of
the terrible things that people have experienced.

Participant 2 also reported concealing his status at work out of fear of what would happen if co-

workers became aware of his HIV status. He stated, "It's like scary, you know - will they find

out or, if they find out, or when will they find out, what they will do? I think that's really scary.

And that's a big stress." This feeling was shared by participant 5, who described her fear when

colleagues at work discuss HIV as part of general conversation:

I absolutely have that fear. Just in passing conversations with
different colleagues at work as soon as the word AIDS or HIV
comes up … ultimately if anybody were to have it based on just
comments made, yeah, it would be not a very cool place to work.
Very much a stigmatized environment to discuss that very word.

Two study participants reported not disclosing their status out of fear of being terminated. In

both cases this was due to similar negative experiences they had witnessed in the workplace. For

instance participant 26 described observing a colleague being terminated unfairly:

There was this other guy and he was very promiscuous, he
eventually got fired. I never disclosed to them because I could see
the way they were very uncomfortable with it… Some of the board
members were uncomfortable with gay people in general.

Participant 22 described a similar experience:

A participant here who got a job at the force… was doing really
well there for two months and had a great relationship with his
manager. They were talking one day after hours about how good
he was doing, and she was saying things like, "I am going to put
you in for a raise, we are happy with your work, everything you
are doing is really creative." Then in that conversation he told her
that he had HIV and that was the end of the conversation. They
kept doing what they were doing. Then the very next day the
owner of the business called him in, and terminated him. So things
like that remind me this is a really un-educated world... the
manager as he was leaving said, "I'm really sorry I had to tell him.
He does our health and safety stuff so he has to know." Why did he

have to know? What health and safety issue is there? So he got
clarification that he was terminated because of the HIV.

For several participants, disclosing their status at work was a risk that presented undue

consequences. However the unintended effect of concealing the disease in this manner was that

these participants continue to be excluded from the full benefits of working. Participant 22

described the psychological and physical toll that hiding his status at work had on his health:

I wanted to get into keeping my health secret. I couldn't tell my
staff. I couldn't tell my customers. I couldn't tell anybody around
me except my partner that my health was an issue, or that I
couldn't afford my meds. It added to the anxiety, so I had a lot of
anxiety that year too. I know it has a huge effect on my health.

For some participants the fear that others in the workplace would find out about their health

status was a considerable preoccupation. Participant 8 described his fear of looking ill to others

in his workplace:

I was really lucky for a number of reasons... I always looked
healthy, I didn't look sick. It was always something I dealt with in
the background where anybody... say you got sick and you had a
job, and you didn't look well, which a lot of people didn't, then it
became known at your office and then you had to go on disability,
and then you had to fight back, because that was a whole different
battle.

Furthermore, participant 5 described her concerns about involuntary disclosure and her fear that

her workplace benefits providers would require her to disclose, potentially limiting the type of

benefits or services she was entitled to. She recalled, "To take on additional insurance coverage

such as critical care illness, they have those health questions, so I just avoided those like the

plague, and I was just like give me my basic coverage that I'm entitled to."

Gender and racial differences related to the ability to publicly disclose the illness were

evident among participant narratives. Women who had children, or family and caregiver

responsibilities reported being less likely to disclose their status at work as they felt responsible

for any consequences family members may have faced due to their disclosure. Additionally,

newcomers and recent immigrants were often concerned about their status being breached among

familial and community networks and that this news would reach their country of origin. This

issue was especially relevant for participant 24, a wife and mother, working part time in the

family business. For her, work, family, and community were closely intertwined and although

she was conflicted about wanting to disclose she was also hesitant to contradict her husband

(who remained undisclosed) and burden her family:

> So you know, there's like this aura of everybody knows but nobody
> knows in the community. I'm sure it happens for a lot of Africans,
> and maybe it happens for non-Africans too. I am much more open
> about stuff, and I don't feel like basically lying. I lie to my kids
> about where I go, and my son is starting to be curious about some
> of the stuff that I do. I would love to tell them, but we haven't even
> told our kids. I'm totally keen to tell them but then I waffle back
> and forth because I think that's putting a big burden on them.

Participant 4, a recent immigrant and a single mother, also reported wanting to share her status at

work but was being discouraged by a personal friend and co-worker:

> My friend, when I tell her that and when I say I want to tell others
> about my disease, she says, "No they can't take it. It is better to
> stay quiet." I just stay quiet, and to stay quiet is a challenge for me.
> I want to show her at every chance, every day, that I can do
> something for myself. When you do something when you are sick
> like this it is better to tell someone, and try to share it. I don't have
> to stay like this.

For those participants who were newcomers to Canada or recent immigrants there

appeared to be an added motivation to conceal the disease. Participant 15, a recent immigrant,

described a sense of isolation resulting from his inability to disclose his illness at work or to

others in his community:

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Interviewer: Would you ever disclose that in the work place?

Participant: No. Oh my God, I can't. There were 200 employees and they… the Canadians that work there are all from the east from [another province]… they are very rude how they treat each other… I never tell anybody, and I would not. The only place I can safely disclose my HIV condition is here at [community agency]. I wanted to participate in the speaker's bureau but probably I can't do that. Not in my work place, that is not the proper place to tell anybody.

Participant 6, a single mother, fully acknowledged that not everyone finds themselves in situations where they are able to be open about their status, explaining how culture and parental status can intersect creating a negative impact on one's ability to disclose:

If you're one of the lucky people that you are in a different place in your life, and it doesn't matter if people know your status. Those are the lucky people. But, you know, for some people like me who is a mother, I am not the only one I need to think about. So, very few people that I know, that are having their dream jobs. It's, it's a compromise and at the end of the day you have responsibilities.

Participant 4 further discussed the sense of vulnerability she felt at work as a main reason she would not disclose her status:

According to the behaviour of my boss I would say no because what was important to her was, are you working or not. When I came and I said, "I'm sick," she was nervous. I said, "Oh I am sick but I will come to work," and she was not supportive. Imagine if I could tell her that I was sick because I have this problem [HIV], imagine what she would do.

Those participants who concealed their illness at work did so out of fear: fear of others' reactions, fear of rejection, stigma, discrimination, and other consequences. In some cases these fears were well founded and based on past negative experiences. Participant 2 recalled disclosing to a past employer and the negative reaction he endured as a result. He stated, "You know, I did tell the owner and..... he made comments like, 'Don't touch me; I'm going to get a disease.' He

did make negative comments which were very upsetting." Additionally, several participants were

fearful of involuntary disclosure or having their confidentiality breached by co-workers or

employers. Indeed, some participants described painful experiences where this had happened to

them in the past. Participant 14, a full time employee in the financial services sector, recalled

having his confidentiality breached by several parties including insurers and managers:

> I guess long-term disability communicates with your manager. At
> that time.... I guess people were asking about me, which is fine,
> and this individual went on to say different things that brought
> things to attention and there were key words that were mentioned...
> I don't really know what was exactly said. I wasn't there. But then
> I got phone calls from individuals at work. And that's where the
> questions came in. They give you that phone call asking how you
> are and then they say, "Can I ask you something"? and I said,
> "Where did you hear this"? And there was things like, "Oh his
> blood work's not very good." Long-term disability communicates
> saying I'm not returning to work because my blood work's not
> doing well? Why are they communicating that to the staff?

Participant 12 described how his confidentiality was breached after confiding in several co-

workers:

> I had two co-workers that knew and information leaks really bad. I
> remember once when I was working at a big reception for 200
> people… I was not feeling good; I could not pack everything
> because I was bar tending. I said to my boss, "I need to go," and he
> said, "Why didn't you tell me before"? I said, "Because I promised
> you yesterday that I was going to work for you." He said, "You
> should call me before you get here because I know your situation."
> Then I found out he probably knows.

These breaches of confidentiality created undue stress and anxiety for both participants.

Furthermore, a couple of participants reported additional and quite serious consequences related

to involuntary disclosure. Participant 6 reported how she had to abandon her career as an

educator due to community gossip about her HIV status. She recalled, "Right, you see, I tell you

I can't go to teaching because I've experienced supply teaching disclosure. My status has been

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disclosed, that's a barrier." Participant 9, a social worker, described an incident where his co-workers breached his HIV status with his clients, an incident that led to a significant alcohol relapse and the loss of his position at the agency:

> We had a co-op house for students to help get them off the street, and my client happened to be living there. I had gone through a period of illness and my client asked the co-op coordinator "what is going on" and he told her. She went in to her job and her job actually called me because she came in crying with tears in her eyes because I was dying… I spoke to the Executive Director and said I want this addressed.

Whether having experienced this directly or simply having seen or heard about such situations, these experiences eroded participants' abilities to trust their co-workers and meant that they would be less likely to risk disclosure in future scenarios. Thus, many participants actively concealed their illness in order to protect themselves from a broad range of feared consequences including stigma, discrimination and possible termination.

6.2.3.2 Selective Disclosure

Those who were able to conquer their fear of disclosure and find safe and supportive workplaces reported being better able to thrive within their workplaces and were more likely to fully contribute to the workplace and community life. Several participants described managing disclosure "episodically" meaning that they selectively disclosed their status at work based on their assessment of the environmental conditions and the level of trust and support available. When managing disclosure, several participants reported that it was very important that they were able to control the disclosure and always had the option of choosing whether they felt it was an appropriate forum/situation in which they wished to disclose.

In cases where participants chose to selectively disclose their status in the workplace, they did so while still fearing gossip and involuntary disclosure; therefore, protecting themselves

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from other co-workers remained a critical goal. Nevertheless, these participants described this

approach to disclosure as having distinct benefits, including providing added social support and

access to accommodation. Participant 17, a young gay male working as a waiter, described

disclosing his illness to a few trusted co-workers, a strategy that enabled him to access needed

social support and to which he attributed his success at managing the demands of working:

> I have a couple of really close girlfriends there who I've revealed
> my HIV status to... if I hadn't told those few girls, I just feel like I
> would be going into work, into some sort of closet where I'd have
> to really hide everything. If you don't have those close people at
> work to be able to talk to you, and relate with, and be there for you,
> then work is just, it would be a disaster for me. So they really are
> part and parcel of what makes me keep going.

Similarly, participant 23, a manager in the private sector, described disclosing his diagnosis to

his supervisor:

> On the day that I got my diagnosis, it was kind of pretty
> devastating, and my boss just happened to walk into my office as I
> got back. I was about to go home, and I kind of blurted everything
> out to him. I didn't mean to because probably I wasn't thinking of
> what the ramifications of that potentially could have been, but he
> was absolutely, amazingly supportive… I'm in a fairly senior
> position as well, and for me that was the biggest thing. If I want to
> tell people, it's my business. I have told people but I don't believe it
> dictates who I am at work.

Participant 1, a federal government employee, reported not trusting his peers but disclosing his

status to select managers with whom he had a good relationship:

> The first person that I told was my Director, who is two [levels]
> above me... When I came back to work my previous manager had
> come back but was re-assigned. So, I told her. These were,
> ironically, when I think about it, all ladies. I felt that I could trust
> them. I would not tell the person I reported to or peers.

While the decision of whether to disclose or not was a difficult and risky choice faced my many

participants, some individuals described advantages to being disclosed including the ability to

gain needed supports and resources. This is in contrast to those who lose specific benefits when

they conceal or hide the disease.

6.2.3.3 Public Disclosure

At the far end of the disclosure continuum were several participants who chose to

publicly disclose their HIV status. Contrary to concealing the disease, these participants reported

managing disclosure publically and strategically both as a means of contributing to their work

place and their community as well as enhancing their career options. Many of these individuals

perceived their workplaces as supportive environments where they felt comfortable being

publically disclosed. One example is participant 30, a gay male who recently immigrated from

the U.S. to work in the travel and hospitality industry. In contrast to participants who were hiding

their status, he did not view his illness as a secret that he must protect from others:

> I had trouble understanding why people freak out like it's a secret.
> If you treat it as a deep dark secret that should never see the light
> of day people will react that way. But if you say, "I am HIV
> positive," and it just comes up in regular conversation or just being
> gay or whatever people don't have time. They are like, "oh." So
> that is the way I have always dealt with things.

This was also the case for participant 18 who has worked in various roles within the AIDS

movement, including as a public speaker. He described how through public disclosure he was

able to control how he presents HIV to the world around him and how this has enriched his

personal career trajectory as well as the organizations to which he contributed his skill and

experience as a person living with HIV:

> Instead of having HIV control me, I have a control over the HIV
> and how I show it to the world. So when I started working for the
> [organization], I used my HIV status as not a pulpit but as a
> soapbox to stand on and to say, "The only reason I'm alive is
> because I have had access to medication, millions of people in
> developing countries are going to die." In that way I turned it

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towards my advantage and used it as something to move me
forward.

Participant 6, a women working in an AIDS service organization, discussed a similar openness

about her status as well as some of the challenges and pressures associated with this leadership

role:

> When you work in an ASO, and you've been in a space where you
> want to disappear, right, and those same peers come into your
> workspace, and you're providing support to them, they tend to look
> up to you as, as if you are past the struggles. So, sometimes you
> find yourself just putting on this persona, like, everything is cool,
> you know, just to keep them going. My biggest challenge is I think
> sometimes I strive too hard to prove a point that women affected
> by HIV can be anything.

Participant 29, also an AIDS service organization employee, credited his job with providing a

safe enough environment in which he could risk openly disclosing his status as a person living

with HIV:

> I think because it's an ASO, yeah, it's no biggy. I don't know if I
> would in another work situation if I got a different job... I don't
> know if I would do that or not. Part of me kind of thinks well it's
> not an issue for me, but it might be an issue for someone else so I
> tend to… reveal it. It's not all of me, but its part of me, part of my
> story.

The phenomenon of being publically disclosed was not one restricted just to AIDS

service organizations. A couple of other participants were publicly disclosed within other types

of employment situations Participant 31, a nurse, described how support from the labour union

had provided a measure of safety such that he felt comfortable openly disclosing his HIV status

at work:

> The union is a big support, and my employers also a support. My
> employer knows, so there is no secrecy there. I have disclosed. I
> think it's important as a health care professional that my employer

know, both in terms of my safety in practicing and support around
that.

Participant 30, an employee in the hospitality industry, reiterated how being public about his

disclosure had relieved his and others' fear of the disease. He explained, "The fear of HIV is the

big thing, and I think the only way you get over that is just more people come out about being

HIV and you know expose themselves." Beyond the benefits they achieved personally, there was

some indication that those who were public about their status had a measure of impact on other

people living with HIV. They reported receiving feedback from others indicating that, whether

consciously or not, they served as role models for others. Participant 27 described how he

believed that public disclosure helped normalize the illness:

> There is one of the peer support workers working here who did it
> with his boy friend; they disclosed. One is negative, one is
> positive, it helps people living with it know there is nothing to be
> ashamed of. Maybe I should feel bad for not disclosing, maybe that
> would prompt a wave of disclosures, but I don't know.

This was reiterated by participant 26:

> I really respect people who go public with it, I think its awesome;
> it gives a contribution… with being gay the important thing is to
> know. You feel less foreign and less awkward - I know him and he
> is a normal person, and I know he is gay, okay, then it's not that
> bad. So probably the same thing needs to happen with HIV, with
> the status. I don't know maybe in time.

To some, this also existed as a pressure and they were wary of completely losing their privacy or

being considered a token. This was the case for participant 6:

> Sometimes when you disclose to your work or to your co-workers,
> there's a tendency of, not being taken for granted, but people tend
> to ask you. So, let's say there's a conference happening, and there
> needs to be a PHA attending. Sometimes, I find myself in
> situations where somebody can just come and say, "Oh, they've
> requested some PHA to come and speak. Would you like to go"?
> It's not a private setting and then I go, "My telling you doesn't

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give you the right to say it whenever you want to say it." So, it's always a challenge to get privacy in that context.

In summary, all participants reported managing disclosure as an important interpersonal process they engaged in as part of working successfully. Study participants' discussion suggested that a continuum of strategies existed including actively concealing the disease, selectively disclosing their status, and being public about HIV.

6.2.4Managing Relationships

Managing relationships was an important interpersonal process that study participants reported engaging in as part of their vocational success. This fourth subcategory within the interpersonal processes category is closely related to managing disclosure and is characterized by a variety of relationships with others, ranging from hostile to supportive. For many participants, actively managing relationships both in the workplace and in their personal life were key processes that required their attention in ensuring they could continue to work successfully. Whether with co-workers or family members, cultivating positive personal relationships were processes that could help ensure that participants had a measure of support and assistance in facing various challenges related to working with HIV. Participants characterized both supportive and antagonistic relationships as factors that required their attention and reported a diversity of processes including dealing with hostility, isolating self from others, and receiving support from co-workers and family.

6.2.4.1 Dealing with Hostility

HIV remained a highly stigmatized illness in many environments in which participants were working. Dealing with hostility from co-workers was a significant concern for many study participants and was often closely related to their approach to disclosure. Managing relationships

with co-workers who lacked knowledge about HIV was among several workplace challenges identified by participants. For instance, participant 10, a part time cleaner, described the ignorance her co-workers demonstrated; factors that contributed to her decision to conceal her status from them. She recalled, "The way people talk about HIV. My partner in working said, 'Oh that HIV you can get it in a cut, I am scared, I don't want to touch that…' You get scared about the way they talk." Participant 14, a full time professional employee in financial services, also felt that a lack of education among his co-workers contributed to their suspicions and fear of his health status:

> Visually looking at me, you could tell when I was becoming ill…
> the individuals, and the lack of education, the stigma and the
> stereotype came up. Uh, so questions did come up in the beginning
> but I refused to answer them.

Participant 2 also described his experiences with co-workers who he felt were hostile and lacked understanding. He explained, "Working with people that are very immature, you know, 18, 22 year old girls that don't understand and having no support from management or upper management." Managing the unsympathetic behaviour of their co-workers was for many participants a necessary part of maintaining their employment. For instance, participant 12, a waiter working mostly on-call hours, reported how he struggled to deal with abusive treatment from hostile co-workers and how this limited his ability to reach his vocational aspirations:

> One of them changed a lot… because he knew I was on disability.
> He was screaming at me saying, "You guys are taking my money
> that I pay for taxes right"? … I called him 4 or 5 times telling him
> that, "You make me feel uncomfortable, not because I don't want
> to work, it is my situation and my health. Not because I don't want
> to work, I am sorry about your taxes. I don't want to hurt you at
> all, but it is the way I am, the way HIV is. That is why sometimes
> it does not allow me to work, that is why I do not have a full time
> job. That is why I cannot even have a part time job." He heard me
> many, many times.

Participant 1, a federal government employee, reported needing to seek a special workplace accommodation in order to manage and protect himself from negative workplace dynamics:

> There are so many personality conflicts and issues. Even other
> staff that get stressed out... they'll try to burden you with it.
> There's an awful lot of that stuff that's going on. Before, I could
> deal with it. Before, I could deal with it. It's now, I don't want to.
> I just can't now.

Thus, dealing with hostility from their co-workers was a relatively common workplace process that many participants reported dealing with and managing on a regular basis. Underlying much of this behaviour was the stigma that is commonly associated with HIV, a major vocational factor that will be discussed in detail in following sections.

6.2.4.2 Isolating Self

In reaction to this hostility, some participants reported feeling "othered" in the workplace: experiences whereby they were considered outside or different from their coworkers (Mullaly, 2002) . In response they often intentionally isolated themselves both socially and professionally. In some cases, this contributed to a sense of social isolation despite being active in the workplace. For some participants, withdrawing socially from their co-workers was the best way to protect themselves from possible negative or harsh treatment. This was the case for participant 3 who described his reticence to become socially involved with anyone at work:

> I go to work to do my job, and to get out. I don't want to socialize
> with people at work, and there's not much room for the social
> aspect of work. I mean I could if I joined the social committee but
> then I don't have kids so I don't really see the need to join the
> social committee and interact with people because most people that
> are there either have kids or grandkids. It's an environment that I
> wouldn't necessarily fit into and I'm there to do my job and do it
> well and to leave at the end of the day, go home and leave it there.

Participant 8 discussed his feelings of not fitting in at work and preparing for the worst in regards to co-workers and their behaviour:

> It is very difficult to fit in with the corporate company and the financial business as an HIV person. I've had different reactions in the past, and basically I just take it one day at a time with these people, see how they react and I react after that.

This was also the case for participant 5 who previously discussed her need to conceal the illness from others. She explained, "I choose not to go on a social realm with my colleagues outside of work, you know. A couple of times I go out for a beer, other than that I just keep it very much on a professional basis." Participant 23 also reported isolating himself as his experience of living with HIV deepened and he felt he needed more time alone:

> I was always an extrovert, but that was changing over the last few years anyways just because I deal with people all day. Now I tend to be more introverted, and get more energy for myself rather than needing to be around a whole pile of people. I think that sometimes I know that I can be a little harsher with everyone not just in work but outside of work.

Thus, the impact of hostile co-workers was an issue for some participants including both those who were disclosed in the workplace and those who weren't.

6.2.4.3 Receiving Support from Co-workers and Family

Receiving support from coworkers was also an important process that several participants identified as critically important in working successfully. Despite the existence at times of ignorant or antagonistic co-workers, participants also were able to identify and connect with supportive and caring colleagues who were able to assist them in maintaining their employment. For example, participant 16 described how two very supportive co-workers really made a difference in his ability to maintain his employment:

They take me out, and you know, go out for a drink or maybe go
out for a coffee. Just having that emotional connection is really
important, and they also, although they're both girls, they try to
relate to me, and they always say, you know, they always try to
give a different spin on things. If I'm looking at one side they try
to show me the other side. Just being able to help me out with that
is a very big thing for me to maintain work. When I see them at
work it makes my day better as well.

Participant 31, a full time nurse, discussed the importance of having a network of supportive co-workers to help him manage a stressful job:

It certainly can be stressful, yes it certainly can be. You have to
wind down from that right… But it is important to have a good
sort of network in terms of people at work to be able to sort of
laugh about the stressful situations that happen, and kind of
decompress right so that's really important.

Additionally, even though participant 5 did not disclose at work and refrained from socializing

with most of her co-workers, she also acknowledged that having the support of some of her

colleagues at work was beneficial. She confirmed that, "There is a great bunch of people that I

work with so I've made some really good colleagues at work so it makes the day go by a whole

lot more successful." Participant 28, an AIDS service organization worker described having

supportive relationships with his co-workers, one benefit of which was that they encouraged him

to practice self care and set boundaries. He explained, "I have staff members who are like, you

know, 'You need to go home, you shouldn't be one of the first in and one of the last to leave.' I

set a good boundary, I booked off my birthday, I booked it off." Participant 21, also an AIDS

service organization worker, discussed how positive relationships at work contributed directly to

his sense of well being and effectiveness on the job:

I like having contact with other people, not only clients but
colleagues. I like knowing that every day I have something to do. I
like to create here, my boss is very open to if you have an idea let's
put it on the table, let's work around that. Most of the time he lets

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us do it as a pilot. That is good you feel it is not just your job, you can create, you can elaborate ideas, and definitely they are going to have someone … they are going to respond.

Participants also discussed relationships in their personal life as factors that had an impact on their ability to work successfully. Managing these relationships were important processes involved in working successfully. Many participants reported both relying on support from family members and negotiating hostile family environments. Additionally, some participants discussed the added burden of being a caregiver as a factor that impacted their employment trajectory.

Numerous participants described supportive family relationships as instrumental in assisting them to continue working. Participant 27 explained how having the support of his family contributed to his sense of confidence:

There are a lot of things that contribute to the feeling of confidence. Having a loving family, that is definitely part of it, that gives me a lot of strength for sure. They have been amazing for me in everything. I am just so blessed I have an awesome family.

Participant 31, a gay man dealing with both HIV and addiction described how supportive family members can serve as an emotional and financial backup when things don't go well in life and at work:

They wanted me to be drug tested, and I could not do that at the time. So I went off, and my family supported me for a number of years. I was admitted back in to the hospital a couple times, and a second time, and a third to the hospital. I actually got some help that I needed.

This notion was reiterated by participant 14, who relied on his grandmother's financial and emotional support, but was cautious about not burdening her with too much:

Um, my Nanny, who's my grandmother. It's kind of odd because she's 84. She's from a different generation. Her communication's

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so open. I can tell her anything, but I don't disclose a lot because I don't want to make her frightened because she's very supportive. When I was worried about my food and stuff like that I can't remember what was said. She's very well off. My family is very well off. There was money in my account, that kind of thing.

Participant 2 also discussed how he maintains a balance between keeping his parents informed about his illness without discussing it too much:

My parents are extremely supportive. My mother's a doctor. She doesn't actually know a lot about the disease, but she's doing more research on it. They're very supportive. We don't really talk about it. I did tell them about a month or 2 months after I was diagnosed that I had it. So, they are very supportive.

For some of the gay men in the sample, emotional and practical support from their life partner was filling a gap where traditional family members weren't present. This was the case for participant 14 who described the positive impact his partner has had on his life:

I've been with him for 2 1/2 years. I was positive when I met him. The best experience I've ever had was with telling him. And he's been supportive ever since, from day one. Um, see and I even get emotional over that.

This was also true for participant 2 who explained, "Well, my partner's negative. My partner's insanely supportive." For participant 3, who drove a school bus, simple and practical support from his partner was instrumental in assisting him to manage his daily schedule:

Well the fact is that my alarm goes off, and I still can't wake up. The biggest support that he gives me actually is the fact of getting me up in the morning. Once I'm awake there's no question that I'm going to get up and do what I got to do, but there are some mornings that I don't even hear my alarm until he's poking me and telling me to get up. That's the biggest support that he gives me in terms of making my employment work.

In several instances the complexity of the issues study participants were dealing with proved too challenging for some close family members and created stress on their relationships.

For instance, participant 14, a gay male struggling both with HIV and chronic mental health issues, described how his family was able to be emotionally supportive but only up to a certain point:

> When I was first diagnosed, my family was very involved. My parents are.... they're in their 60's; they're part of that generation with the stigma attached. They just don't want to accept it, what they call my choice of life style. But they were very supportive up to when I crash and burned, and I guess they don't understand. And I guess with that kind of thing comes fear. There was a point where I was, I'll just call it what it is – a freak out, when I was moving out of my apartment. I've never been evicted before, and I went through one of those manic episodes and I just, at that point in time, things were not good. And I told my father and my mother, everything. I told them my counts [CD-4] were like 110, or 115. I told them what it means, and that I'm moving and this, that and the other thing, and at that point I did, well I've been told to be prepared for this kind of stuff. I got a phone call back an hour later and my Dad yelled at me. He said I was on drugs, and I was drunk, and all this kind of stuff, and he said never to speak to them like that again. At that point, I didn't speak to them for close to......I would.... um it was Mothers Day, the following Mothers Day. And at that point I, still to this day, I keep my distance.

Describing similar circumstances, participant 14, a gay male, described how the stress of living with HIV compounded with his addiction led to the break-up of his marriage. He recalled, "When I went psychotic my husband kicked me out and he sent me to live with my parents, I lost my job, I lost my husband, and I lost my house, I lost everything, and all my friends scattered." Also dealing with multiple and complex issues, participant 9 described how he needed to break ties with his family in order to deal with HIV and his chronic addiction:

> I also had a very dysfunctional family history. As a matter of fact when I sobered this last time I broke contact with the family. They are active alcoholics as well, not drinkers they are like drunks, and I realized that I need to take a break from that too. I just reconnected this past year. That was a result of my step father being in the hospital, he fell down and broke his hip. So we are talking.

For many of the women in the sample the added burden of being a mother and the

primary caregiver for their children was a factor that impacted their employment trajectory. In

addition to working, several of these participants were managing the complexities of raising

children alone and with little help. This was certainly the case for participant 6, a single mother

balancing working full time in an AIDS service organization with caring for three children:

> So, with the dynamics of my family, I can tell you that I'm crazy.
> I have a child with first year university, I've a grade twelve, and
> then I've a four year old. That's one for the road. The challenges
> that I, usually face, I just balance it … making sure that, you know,
> all day care things are in place, have I gone to all their
> appointments?

Participant 5 described her challenges raising children while at times also feeling ill:

> Yes, my children are ultimately older than what you might think of
> as far as child care is concerned. But certainly five years ago when
> I was sick and my youngest daughter didn't want to go to school
> that certainly played a role in how fast I was recovering because I
> was stressed out.

Participant 10, also a single mother and a recent immigrant discussed how she balances work

with caring for her two children:

> I have two kids, one she was born in Africa she goes to school, and
> she is in university. But this one is born here, I live with this one
> here. She is 14 years old… yeah. It is hard. It is very tough. It is
> hard, like I don't have any one to help me, like with finances, and
> when working sometimes I am too tired… And there is no one to
> take care of your kids you have to do it alone, it is hard, I have no
> family here.

In addition to being a caregiver and single mother, participant 5 explained how her children were

also an important source of support, one that assisted her in working successfully:

> My oldest daughter was one of my biggest supports to help me
> through that sickness and transition back to work; getting me
> dressed, brushing my hair because I was just not able to do

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anything. She was my Florence Nightingale, my daughters and my
family.

Managing relationships is an important interpersonal process that study participants

reported engaging in as part of their vocational success. For many participants, actively

managing both supportive and hostile relationships in the workplace and in their personal life

were key processes that required their attention. Cultivating positive personal relationships and

addressing and managing hostile persons in their life were processes that could help ensure they

had a measure of support and assistance in facing various challenges related to working with

HIV.

6.2.5 Employing workplace skills and coping strategies

Employing workplace skills and coping strategies is the fifth and concluding subcategory

in the interpersonal processes category. Participants described a range of workplace skills and

coping strategies they applied in order to work successfully. These included managing vocational

transitions, managing stress, leaving poor work matches, and managing time effectively.

6.2.5.1 Managing Vocational Transitions

Several study participants recalled needing to manage periods of vocational transition

such as first starting work or returning after an episode of illness. Several participants

acknowledged that these times of transition were periods where they were vulnerable to illness

and where they needed to ensure that they employed effective coping strategies in order to

continue working successfully. For example, participant 3 described needing to manage the

transition back to work after being off for a week:

> The adjustment period… in March, it was coming back from
> March break. I had a week off, and I attribute that to the
> adjustment period to me getting sick. My body is going like what
> the heck's going on so that's the impact other than nothing major.

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Participant 11, working full time in an AIDS service organization, also struggled to manage the

impact of transitioning back to work after being home for a longer period of time:

> And I just found that having been out of work for 18 months and
> coming in first of all just working 5 days a week by myself was a
> shock. You are used to a pattern of getting up in the morning,
> going to the gym, maybe doing this or that, and then all of a
> sudden working 5 quite long days. It was a bit of a shock.

Participant 29, also an AIDS service organization support worker, described how he employed a

gradual return to work as a strategy to manage the shock of this vocational transition:

> Luckily for me I started gradually, that was 1day a week. It may
> have been 1 or 2 days a week. I worked there for maybe about 3
> months until this job came up. So that was a good prep to get me
> ready to come back, you know, 4 or 5 days a week. I was just
> thrown right in to it. The first while I was tired but I was glad that I
> got to kind of gradually get in to it.

Thus finding strategies to manage vocational transitions were important for several participants,

especially since they acknowledged specific health vulnerabilities during these periods.

6.2.5.2 Managing Stress

In addition to the challenges associated with management of an episodic condition,

several participants described their jobs as also contributing to their stress. Most study

participants reported a number of stressors in the health and vocational realm as well as needing

to manage this stress as part of their ability to work successfully. Specifically, several study

participants reported that they perceived increased levels of job stress as negatively impacting

their health, that they were less able to handle stress as a result of their HIV status, and that they

utilized a variety of strategies in order to manage this stress.

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Several participants described their vocational role as an added stressor. For instance, participant 8 described the kind of stress he must constantly handle while doing his job in the financial services sector:

> Sorry to tell you that it is really a little stressful. I'm on, negotiating all the time, and I have to be really quick on my feet to think through problems. It's really problem solving under stress, is what it is.

Participant 19, a full time employee in the health sector also described the kind of stress he feels on the job:

> Oh yes. It is being stressful because as a coordinator you are supposed to provide ongoing structure and support. It was fine when I had 30 participants, or 40 participants, I now have 80. By the time you check through the e-mail account, you check your messages, over half the day is gone. You maybe will give one report, I am 2 months behind in report writing.

Several participants perceived increased work stress as having a negative impact on their health. A factor they mitigated by adopting a variety of strategies. Participant 1, a federal employee, noted how his stress at work was connected to multiple health factors:

> The other thing, which is really major, is stress control. I have found that to be so major. I think it affects my blood count. Because when you get under stress at work it's not just something that's for an hour or 2. It can last a week or a month depending on what the source is. Your eating is so important. Your eating habits, stress will even change that. And all these things affect your blood level, your CD4 count. I kind of try to keep tabs and be educated about it.

Participant 14 acknowledged that job stress also affected his health and noted that striking the right balance was helpful in working sustainably. He explained, "There was a stress level that came about which interfered with my eating habits again. My counts did go down. They didn't drop dramatically but once that stress level was eased I found that it was okay." Participant 2, a

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gay male balancing part time work and study, also reported that vocational stress had the

potential to affect his health. For him finding vocational opportunities that matched his stress

management skills was an effective coping strategy:

> I saw that my CD4's and my numbers would drop and I was very
> nervous because of the stress. And it was impacting me in a
> negative way. I realized that I don't want to stop working, but I
> need to make sure that I'm doing the right thing that's not going to
> put that much stress on me or I need to figure out how to handle
> stress better.

Participant 27, working in the education sector, reported the cumulative stress associated with

managing his health and doing his job and studies well. He also talked about how for him

prioritizing his health was important:

> You know the big sum of everything makes for a pretty intense,
> stressful life. I am fine, I choose it after all, I have to say now
> towards the end of the program things were a lot better than the
> first few years... it was a lot more stressful ...but now I have also
> decided that my health is my first priority. Of course I want to be
> done [my educational program] soon but I have been very clear the
> number one is to stay in good health, everything else is second to
> this first priority that I have, I am fine with it.

In addition to work, participant 5, a single mother, acknowledged financial pressures as a source

of stress and noted that this often manifested itself physically:

> I'd like to ultimately pay off all of my creditors, but you can't
> satisfy everybody. I just do what I can, and when I feel like it's real
> stress, right in the core of my head is where everything sits for me.
> If it means I have to walk outside to get fresh air or jog or have a
> glass of wine or something, I do that.

In addition to noting the impact of stress on their health, several participants also described a

decreased ability to handle stress. For example, participant 9, a part time AIDS service

organization worker, noted that his ability to manage stress was hampered following his HIV

diagnosis:

> I don't know if it is related to HIV, my ability to manage stress has
> gone down. I don't know if that is just an age thing, I am going to
> be 49 in August; I used to thrive on that stuff. I loved it run, run,
> run, and go, go, go. I just felt charged. That does not work
> anymore.

This was also reported by participant 1, a long time employee of the federal government:

> Stress for example, I could work under high stress levels, because I
> loved the challenge. Stress didn't bother me at all. As far as the
> proper eating goes, I could eat at my desk or I could run out. I was
> even the type who would skip lunch. Instead of having a lunch you
> would fill up on coffee. That was fine.

Additionally, participant 22, a full time employee in health and social services, reported that this

diminished ability to handle stress was interfering with his work, a factor that precipitated a

career change:

> The stress level was more than I could deal with long term, and I
> felt myself - I don't know if it was the age thing or HIV - but I felt
> my abilities to keep in control of all the work diminishing.

As noted in these narratives, study participants found ways to mitigate the effect that

stress had on their life. This included balancing work with rest, monitoring its impact on their

health, and setting priorities. Participant 2, a part time employee and a student, also described

finding a balance between work and home as beneficial to his success:

> I also have that ability to, when things do get a little bit stressed, I
> can always take things home and do it there. So, it gives me that
> balance to be able to be in my own environment. Because when
> I'm studying or something, I'm doing it in my own environment.
> So, it's not like it doesn't affect me as much as it would when I'm
> in, like, a working environment. So, I think, like, familiar
> surroundings are very beneficial.

For others, managing stress successfully meant finding positions where the stress was not too

much to cope with. This was the case for participant 16, a full time waiter, who reported being

able to successfully manage the stress he faced at his job:

I'm not trying to say there's no stress, but the great thing with serving is when you are stressed out or you're really busy, once you cash out and go home, done. The next day it's a whole new set of tables and a whole new set of people and unlike an office, the stress doesn't carry. I know in management it does carry, but I think for my role it doesn't. So I'm just kind of cosy right now.

Additionally, participant 5 described actively managing her stress by using exercise and physical activity:

when I feel stress I feel it in the back of my neck, and I've been doing running, Pilates, and I've got a bike coming tomorrow. I'm just I'm trying to do different outlets to just not be so bogged down by the stress. Because we're gonna have stress no matter what.

For some, setting clear boundaries between work and personal issues related to health and HIV were also strategies for coping with stress. Participant 21, a student and part time employee, reported struggling to stay focused at work despite the personal stresses associated with his illness:

I think everybody is having ups and downs. And it's trying to be focused on our work, and not letting external things or personal problems affect it. I always see that that personal problem directly affects your health, you know? Especially stress or depression and those are the moments where I see that oh my God I really need to do this, to stay focused on my work, and not let these interfere.

Participant 8, a financial services sector employee, also described putting his personal issues on the backburner so as to maintain his focus at work:

When I go to work … HIV is the furthest thing from my mind. It's something on the back burner right now that won't even come up. It's a very private thing. I'm able to separate that okay, where a lot of people can't separate things. They're a little bit fuzzy. They want to bring all their problems to their work, while I just leave everything and just focus on what I'm doing. Right. So that's another problem. You have to separate your own health care and situation from your work and then, you know, don't get too emotional about it.

Separating personal issues from his work role was a coping strategy utilized by participant 9, an AIDS service organization worker, who acknowledged needing to do so in order to be effective when working with other people living with HIV:

> Not just at work but stress in general. I manage to put it aside when I am here… I look after myself and if I get triggered I am fortunately able to recognize, "Oops, that is yours, put it over here for now.' Then I talk about it with my co workers or somebody as soon as I can.

Thus, employing strategies to deal with stress, both work and illness related stress, was an important skill reported by several participants as contributing to their ability to work successfully.

6.2.5.3 Leaving Poor Work Matches

Finding the right vocational match was an important factor in vocational success for people living with HIV interviewed for this study. Many participants in this study reported a high level of satisfaction with their jobs and having a passion for their work, both factors that contributed to their success. Additionally, many study participants described a process of leaving poor work matches prior to finding the right vocational fit. In some cases this was due to the previously described levels of stress in some workplaces or the need to prioritize their health over work. For instance, participant 2, a part time employee and student, discussed leaving an earlier stressful position in order to preserve his health:

> Eventually, I did resign because … even though I say that I'm healthy enough to work, I still am not going to put myself into positions where my health and my sanity and everything else is risked. If I do put myself into a position where it is too stressful, I will leave. At the end of the day my health is still number one. I will never stop working but I will not put myself into positions when I'm crazily stressed or I need to figure how to deal with it. But this job was never going to get to the point where I was able to fix the stress.

Analogous to earlier categories, the importance of vocational fit was again described by several

participants as being an important factor. This was the case for participant 11, an AIDS service

organization worker, who described his experience in a previous situation before finding his

current position:

> I also found there was no mentorship, it being a small organization
> with five staff, four staff, and myself… I found there was not a lot
> of recognition. My experience was different than their experience,
> I was tired when they were not feeling tired. Maybe I was tired or
> sick. I don't think it was a good fit.

Other participants reiterated the need to accurately assess the demands of a job and be realistic

about what they are able to cope with given their specific health challenges. Participant 6,

described using this skill when deciding to leave her original profession in education for a more

manageable job in an AIDS service organization:

> I tried for a very long time, and I know I worked very hard to try.
> I'm a teacher by qualification and I tried to go back into the
> teaching field, but the demands, you know. I don't know whether I
> gave up too quickly but it was clear I was not going to cope.

A few participants described leaving jobs in which they felt poorly treated. Rather than disclose

his status in a hostile workplace, participant 28, a gay male, decided to leave for a more

supportive workplace:

> I was working in a role that was not a nonprofit organization. It
> was a very corporate sporting venue, pretty homophobic on a
> regular basis… so to go from very supportive environment around
> health and health issues to being in a venue that was you know
> pretty homophobic was different. It was a job and it was something
> I needed to do at the time. But certainly did not feel comfortable
> disclosing to my employer at the time, this was like 16 years ago.
> So I left to take care of my health.

This was also the case for participant 4, who decided not to return to her previous job due to lack

of support from her manager:

> I left my other job because I was sick. During the period of January
> I was in my bed, and because of the behaviour of my boss, and if I
> was to go back now she would say, "If you are sick again you
> won't come and you are required to bring a letter from the doctor."
> I didn't want to be treated this way and so I quit.

Hence, high levels of stress, lack of vocational fit, and the need to prioritize their health led many participants to seek out better employment conditions. Being able to accurately assess vocational conditions was a strategy employed by some participants to secure a position that matched their vocational needs and aspirations.

6.2.5.4 Managing Time

Managing time effectively was an additional workplace skill that some participants identified utilizing in order to better handle work and illness related issues. Participant 23, a manager in the private sector identified these skills as critical to his success in balancing work and life with HIV:

> I'm really good with time management. I know I have to do things
> effectively and quickly, and so by using those skills and … if I
> manage my time effectively I can sometimes take an hour on
> Thursday and have everything done. On Fridays I don't go in until
> 11:00 so my full week is really till Friday, but I've got Thursday so
> it's kind of really like managing that time, prioritizing.

Participant 9, a part time employee in the health and social services sector, acknowledged the need for these skills as factors in progressing to full time employment:

> Just scheduling, and I don't mean just work stuff; when am I going
> to clean my apartment, when will I get laundry done, or get
> groceries? That kind of stuff. I'm sure I would work that out in a
> period of time, I am pretty good at getting to that organization
> state.

Being able to schedule his time effectively was also critical to participant 2 who was balancing the demands of part time work and study:

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> A lot of it deals with my organization. Like I was telling you, I
> have an iPad with all my information, I have a phone, I have a
> notebook so I keep it very balanced... For example, like last week,
> the days that I worked, I was all about merchandising the store,
> make it look nice...and yesterday I studied and I dealt with clients.
> I need that balance between being able to work, and deal with all
> the clients, and help them out and be able to study.

Participants in this study highlighted specific workplace skill sets that they drew on in addressing various vocational and health related challenges. Successfully managing vocational transitions, managing stress, leaving poor work matches, and managing time effectively were all strategies employed by study participants.

6.3 Chapter Summary

In summary, this section identified and discussed the *interpersonal processes* that characterize participant's success in the workplace, the second major category in this conceptual framework. These relational processes are primarily attributed to social networks, relationships, and interpersonal dynamics that influence success in the labour force. Within this category five interrelated subcategories were identified and discussed each of which defined and described a set of interpersonal processes that participants described as essential to working successfully. These subcategories: developing resilience, advocating for self, managing disclosure, managing relationships, and employing workplace skills and coping strategies, were each described in detail and will be further highlighted and discussed in following sections. Again, it is important to keep in mind that these categories are conceptually fluid rather than fixed processes. As such they are interconnected, overlapping, and mutually influencing. The description of study findings will continue in Chapter Seven which will discuss the institutional and community level factors.

CHAPTER SEVEN: INSTITUTIONAL AND COMMUNITY STRUCTURES

7.1 Introduction

As discussed earlier, the purpose of this study was to develop a conceptual framework identifying the factors that shape and influence the successful labour force participation of people living with HIV in Canada. The findings of this study are identified and discussed in several chapters. Chapter Four served as an introduction to the findings, Chapter Five identified the intrapersonal level factors, and Chapter Six described the interpersonal factors. This chapter will focus on the findings related to the fourth and fifth and major categories in this framework – the institutional and community structures that influenced participants' labour force experiences and were connected to the overall process of working successfully.

7.2 The Key Structures

As introduced in Chapter Four, data from this study have been conceptualized within an ecological framework that describes and explains the key categories shaping participants' experiences of working successfully. Often the purpose of an ecological model is to focus attention on the environmental influences on behaviour and to identify environmental interventions (McLeroy et al., 1988). Thus, these models tend to focus on the nature of an individual's transactions with their social and cultural surroundings whilst allowing for the division of the social environment into discrete analytic levels (McLeroy et al., 1988; Sallis et al., 2008). Social structures and institutions are important environmental factors in ecological models that may serve to provide resources and support people in coping with difficult life transitions (Gitterman & Germain, 2008).

An ecological perspective is an important frame for conceptualizing HIV and labour force participation, because issues pertaining to discrimination and structural inequity often

figured prominently within participants' social environments and influenced their employment trajectories. During interviews for this study, participants identified a variety of environmental and structural factors as influences on their employment experiences. These factors existed at the institutional, community, and public policy levels (Sallis et al., 2008). Factors at the institutional and community levels will be discussed in the following sections while Chapter Eight will focus on the public policy level factors.

7.3 Work

The category of work is an important institutional level of consideration and comprises the fifth category in this framework. Within ecological models, social institutions and organizations are seen as influencing behaviour (including vocational trajectories). Organizational characteristics including rules, regulations, and policies for operation are considered important factors for consideration and analysis (McLeroy et al., 1988). In this study, the key institutional factors shaping participants' employment experiences were those related to work. Accordingly, vocational structures at the institutional level such as workplaces, policies, services, and professional groups comprise important factors within the institutional category of work (McLeroy et al., 1988). This section describes participants' experiences in the workplace. During study interviews, participants identified workplace environments, workplace accommodations, workplace policies and benefits, workplace stigma and discrimination, and workplace barriers faced by immigrants as important factors. Each of these subcategories will be discussed in the following section.

7.3.1 Workplace Environments

Working in a generally supportive workplace environment was seen as essential by many study participants. Several attributed their success to working in an affirmative and

accommodating work environment that recognized their contributions, and provided effective management. A number of participants characterized their employer as being generally supportive. Participants 23 and 1 summed up their experiences working for what they felt were supportive employers. Participant 23, an executive in the private sector explained, "I am not going to sit here and preach that all employers are wonderful. I just happen to work for one that is." while participant 1, a federal government employee, enthused, "My employer is probably one of a large number of employers that could be a model for people with HIV. The thing about it is that to me, they've treated me like gold."

Several participants described the factors that they felt helped to create a supportive environment. For participant 5, feeling recognized by the employer was part of what went into creating support in the work place. She explained, "They look upon community outreach volunteering as very good, so they've donated money to the organization that I do outreach with. They also have other employee achievement awards where they recommend employees on a quarterly basis." Trust between employee and employer also played a key role in creating a supportive environment. Participant 5 went on to describe the sense of trust she had been able to build with her employer over a period of several years, and her faith that they would support her if she developed an episode of illness; explaining that, "If anything were to come up, I know that my employer would work with me." Other participants described how a sense of mutual trust between them and their employers helped to create a positive environment. Participant 23 elaborated on this and described an environment of trust and flexibility he had created with his employer:

> I never get questioned about the hours that I keep because the work
> always gets done, and they can see that I'm doing it, and I'm not
> saying, "Pay me because I did some work on Sunday." I give and

> take, and as long as I'm given the same give and take it is usually
> pretty good. I have a trusting relationship there, and I should
> because it's quite a mature role that I have. They've given me
> responsibilities and they trust me.

This kind of arrangement was also described by participant 1, a federal government employee,

who appreciated having some independence at work:

> I don't take a regular break or lunch… If I need a break I will take
> a break to go out to have a cigarette … They don't look for where I
> am. They don't ask where. They know I'm right back, I guess.

Thus, trusting and flexible work environments contributed to participants' confidence and their

ability to work successfully.

Several participants also indicated that the role of the manager was critical in creating a

supportive workplace. Having an understanding manager who was willing to play a leadership

role was identified as contributing to trusting and respectful workplace environments. These

relationships were at times pivotal in gaining recognition, securing accommodation, and

successfully sustaining employment. For example, participant 8, a financial services employee,

recalled how having a supportive manager was critical to gaining access to HIV medication in

the early years of the epidemic:

> This lady was really a pioneer in her thinking. I mean, she would
> physically give me a hug when I left her office. She was really,
> really nice, and that's important. It came in really handy, because
> my company's going to support me, and it helped me get this
> medication I needed. And, you know, if they're treating you with
> this type of support then I'm in good care, right? It was a good
> thing.

Participant 21, a gay man working in an AIDS service organization, described how having a

supportive supervisor helped him manage his physical and mental health while working:

> I am being very open, honest and sincere. I have been telling my
> boss I am not feeling well, I am going through this depression. I

am going to try to focus to definitely meet that timeline. But if I
just made a mistake, just let me know, this is not me. I am just
going through a tough time. He has been very helpful and checking
up, like, "How is everything? How are you doing"? Or sending
little reminders that you need to do. So I think I am blessed
because I have those resources.

Some participants were willing to disclose their illness to supportive managers that they trusted

rather than co-workers or other members of the team. For example, participant 1 recalled how

having a manager who understood the stigma associated with HIV provided him with the

confidence to disclose his illness:

We were peers for quite a few years, and she was very supportive,
and had an awful lot of experience in that area. She understands
the stigma that goes with it. She does understand some of the
mental, emotional, and physical problems that go with it… She
was the first person I told without hesitation.

Although at times protective of his privacy, participant 19 generally appreciated the ability to

have a supportive relationship with his manager, albeit with some clear boundaries:

My supervisor is positive and she is very understanding. A bit
nosey. At times she crosses the boundary friend line sort of thing
right, "Oh, why are you going to the hospital"? It is out of
concern. I can turn around and say it is none of your damn
business, but I answer her because it builds up the relationship.

Thus, supportive managers often set the tone for organizational responses to HIV in the

workplace and were instrumental in creating positive and supportive workplace environments for

some participants.

Aspects of what study participants described as supportive work environments also

involved a manager's understanding of episodic disability. Several participants discussed feeling

free to be open about their illness and receiving support for the need to take care of themselves

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when they were sick. For example, participant 20 compared his current workplace with a past employer where he felt more pressure to hide his illness:

> I saw people that called in sick [at the current workplace], and they told them, "Don't bother to look on to the computer, you are on a day off. Relax; let your body get back to normal. Tomorrow is another day, do what you have to do tomorrow." Not more than that. That is amazing. The first time I heard it, I said, "What is going on?" It is so weird, so bizarre. In [another former workplace] people came in sick, just to be in the office, not to be marked as the trouble maker or the problematic person or whatever… Yeah it was bizarre [at the current workplace], but in a positive way.

Participant 21, an AIDS service organization employee, described how a general understanding of episodic disability within his workplace contributed to the sense of support he felt:

> Everybody understands if I am feeling sick, or if I feel I can't do my job well. I can say, "You know what, I am not feeling good. I am going back home." They really understand my disability. I know when I have been at work that sometimes my days are good, sometimes my days are not good, or sometimes I have long periods of pretty good health, and sometimes I don't have it. So by being understanding that … that is what makes me successful.

Thus, many study participants reported working in a generally supportive workplace environment and several attributed their success to working in an affirmative and accommodating workplace that recognized their contributions and provided effective management.

7.3.2 Workplace Accommodations

Many study participants identified appropriate workplace accommodations as an important institutional factor structuring successful labour force participation. Some participants identified receiving workplace accommodations as a tool that supported their engagement in the workplace. Others discussed difficulties with the process of accommodation such as needing to actively advocate for appropriate modifications or missing accommodations. While no

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participants discussed being refused accommodation by an employer this may be due to the fact that many reported leaving unsatisfactory workplaces rather than risking disclosure or confronting hostile employers. Additionally, in some cases this factor was dependent on disease progression, with those experiencing less episodes of illness being less likely to discuss requiring accommodation as part of their labour force experiences. Nevertheless, required accommodations were often minimal and participants identified three main areas for accommodation: flexible or modified schedules, facilitated adjustment to the workplace, and a change in work duties or responsibilities.

As discussed earlier, many participants reported specific medical needs related to managing their illness. As such, flexibility in terms of work hours and scheduling was identified as an important accommodation that facilitated success at work. Indeed, a majority of participants who discussed accommodation reported needing a flexible schedule in order to manage their illness effectively. In some cases participants received modified work hours as an employer-provided workplace accommodation. Others deliberately chose jobs and positions that offered them a reduced schedule or similar flexibilities. In many cases, these were part time or contract positions. Often, flexibility was required to accommodate medication regimes or to simply manage the multiple medical appointments that many participants were required to attend. Many participants benefited from on-the-job flexibility as an employer-provided workplace accommodation. Participant 1, a federal government employee, described how his employer supported him by offering flexible hours after disclosing his illness, "One thing my employer did is they allowed my hours to be a lot more flexible. They will let me start as early as six o'clock in the morning, if I want." Flexibility in regards to hours was also described by Participant 28, an employee in an AIDS service organization. He explained, "If I need to change

a day in order to do it … they are accommodating and they are going, 'Go ahead, and good for you'." In all cases, participants described requesting flexible hours as opposed to decreased hours, an accommodation that had no cost for the employer. This was the case for participant 23, a manager in a private sector company, who recalled how important this flexibility was in order for him to sustain employment and continue to meet his financial responsibilities:

> I'm an early bird, so I'd go in to work really early, leave early, nap. I'd work my life around my job because I have an ex-wife and children as well that I pay maintenance, for so there was no way I could afford to lose my job. I knew I had to protect my job somehow, and I was in the position where I was able to kind of accommodate myself because I work for a company that promotes employers accommodating modified duties, so it is beholden upon them in my mind to do the same for me.

Participant 21, an AIDS service organization employee, described how this form of accommodation provided great peace of mind. He reported, "It's more about the flexibility of time, knowing that definitely you can flex the time. Coming in at ten, leaving at six, it is a very friendly schedule to work."

As discussed earlier, many participants felt uncomfortable disclosing their HIV status and some worried that they would need to disclose in order to request accommodation. Thus, rather than seek accommodation, some participants preferred forms of employment that offered them a flexible schedule as part of the position structure. One reason for this was medical necessity; several participants felt that due to the demands of the medication and the impact of the illness they would not be able to work full time. This was the case for participant 18, working part time in health and social services, who reported, "I like the way it is now, I need time to take my pills and my side effects are unbelievable." Participant 21 also recalled choosing part time work in order to balance employment with the demands of illness and her HIV medication:

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> The on and off illnesses came when I started working at
> [workplace] because I was now on stable medication and getting
> used to the medication, which is why I opted to choosing a part
> time job, because I could regulate my hours. Mornings were really
> tough. So, although I was working in an environment where they
> were sensitive around the issue it was still tough … and sometimes
> by three o'clock I was totally drained, washed out. So, I opted for a
> part-time job. It allowed me to be at work and also take care of
> myself.

In some cases, decreased hours, or less than full time work was reported by study participants as ideal. Several participants indicated a preference for slightly less than a 40hr work week in order to maintain emotional balance and self care. Participant 17, a part time health and social services employee, described needing this flexibility in order to maintain balance. He explained, "In my perfect world I would be working 25 to 30 hours a week, going to school, training and then having a social life. 25 to 30 hours a week is more balanced." Participant 16, a waiter with variable hours, doubted that he could work full time hours:

> I feel like thirty hours is kind of my max as well. Because I still do
> get burnt out at the end of the week, especially after the weekend,
> which is the busier time. If I had to work forty [hours], I don't
> think I could.

Participant 19 worked in a .75 position within a health and social service agency. This arrangement was an accommodation that he had suggested to his employer as a means to maintaining himself in his work:

> Instead of me working full time, I suggested that I train another of
> my peers to cover my day off. I would give them specific tasks to
> do so I can take a comfortable day off, give assignments, and
> check up on them. So I take Fridays off as part of my self-care. It
> helps alleviate my stress.

For the above participants, having flexible hours was an important factor in maintaining successful employment. Whether as an employer provided accommodation as part of a full time job, or as part of a preference for part time positions; flexibility of hours was reported as critical.

Unfortunately, not all participants were successfully accommodated by their employers in this regard. Several participants identified some difficulties associated with receiving flexible hours as a workplace accommodation. For instance, participant 8, a financial services employee, described the burden of trying to balance his medical appointments with his work responsibilities, which was an accommodation not easily provided for in his industry:

> I've done more testing than you can believe, going to appointments and stuff, so it was difficult managing appointments. Because, in my business, if you aren't sharp when you are at your desk in the morning, then....they had issues with that. They expect you to be at your office at that time. So, you got to go to do a blood thing, you got to arrange an appointment, you got to work around that stuff. The doctors want you to do more tests as you're getting older because you want to make sure that other functions in your body are working. These companies do not understand that type of thing. They just don't give you the time. It was quite tricky all the way from taking your medication to side effects, to actually interacting at work and trying to maintain your health really.

The difficulty of finding time to accommodate medical appointments was also described by participant 14, a financial services employee. Unable to negotiate an accommodation providing flexible hours he felt forced to schedule his appointments around work hours:

> In the [workplace] the computer tells you when to take your breaks for lunches and everything. When you leave your desk you're micro-managed. I see three specialists – ensuring that I'm able to make those appointments is important, provided I give them adequate notice.

Participant 18 acknowledged that taking HIV medication had really limited the kind of

hours he could work. Without an accommodation he felt he had to change positions to one that

provided more flexibility:

> Before the medication, it was easy for me. I could work anywhere
> for 60 hours a week. But after my medication, I had to have
> another position - to work a little bit like 15 hours a week.
> Sometimes only 10 hours, because it is a 5 hour shift.

Participant 6, an employee in an AIDS service organization, acknowledged being accommodated

with time to manage her illness, but described the pressure associated with inadequate resources

to replace her while she was gone; a measure she felt should be in place:

> If a PHA [person living with HIV] is away for long periods of
> time, what happens with their work? I don't want to be away for
> two weeks and still worry about my work. That's not doing me
> any good. It always happens that when you get back to your desk;
> that work is still waiting for you. And people give you room, like,
> one, two, three days but by the third day everybody wants
> something from you. So, I know a lot of PHA's that are very
> overwhelmed. So, ya, that, that's a challenge. Cause if you want to
> help me get better there should be things put in place for that work
> to keep going whilst I am away. And if I know that, next time I am
> really sick I am not going to hesitate to take time off.

In general, study participants were aware of the employers' obligation to accommodate

their illness under existing federal legislation. Despite having a supportive employer, a few

participants discussed needing to actively advocate to receive these accommodations; an act that

frequently required some level of disclosure. Participant 23 was direct with his employer about

his need for flexible hours. He explained, "I've always been really good at knowing how to cover

my ass. I'm good at signing up for what I need to get, so I'd already kind of been able to adjust

my work schedule around my needs." Participant 31, a full time employee in health and social

services, reported utilizing support from labour organizations in understanding his rights in this

regard:

> There is a duty to accommodate. Because of that duty to accommodate my employment is secure; I don't need to worry about that. Having that security is a big peace of mind… knowing my illness cannot be used against me. Perhaps if I did not have the union and the duty to accommodate, it could be used to push me out.

Participant 8, a financial services employee and a long-term survivor of HIV described many

years of fighting to receive the workplace accommodation he knew he was entitled to:

> I'm very familiar with the law; I know what my rights are in the workplace. A lot of these companies ask you to work maybe one or two late night shifts… So, you're talking fourteen hours for a business day, okay. And basically I have gotten into these companies that never provided any, any health care… Now, under the duty to accommodate laws they have a duty now to accommodate my needs. Okay, so, I've gotten in the door, made it through the first three months, I've had to work all these crazy hours … So then, I emailed off these nice letters to these people and I said, "Could you please adjust the schedule, it's really tiring? I'd like to continue working for your company." And they pretty much said, "Well, screw you. We won't do that. You have to work those hours. You agreed to that when you started." I said, "Well, thank you very much for your time." I documented everything.

In sum, while many participants described working for supportive employers who

accommodated their need for flexible hours, some encountered issues or problems receiving

important workplace accommodations.

While flexible hours were the most frequently discussed accommodation, some

participants described other work modifications that were instrumental in their working

successfully. A few participants required a change in vocational responsibilities as part of their

workplace accommodation. One such area was an inability to continue to work with the public.

Participant 29 reported needing some respite from the public as part of his job in the hospitality

sector:

> I would rather work behind the scenes washing cars, or whatever
> because I don't feel like dealing with customers. It really wasn't
> that bad. It's just I had the option to just be by myself and not have
> to deal with customers and this is the reason why. And that's the
> way it was and I never skipped work out of depression … But I
> just kept going.

Additionally, participant 1, a federal government employee, described a successful

accommodation to less public responsibilities; a move that benefited both him and his employer:

> I had a discussion with my doctor and I said, "I just can't work
> front line with the public anymore." It was almost like they were
> aware of it and they said, "We've got something for you". What I
> didn't realize was that when I got back to work that they had a
> meeting with the staff without disclosing anything… So everything
> worked out right… I loved doing that work. It was working on my
> own. I was away from the public at that time. Because I think some
> of the HIV complications in a high pressure work environment,
> when working directly with the public, I think it had an adverse
> affect on me.

Facilitated adjustment to the workplace was an additional accommodation that a small number of

participants identified as being useful. This accommodation allowed these participants to return

to the workplace after an episode of illness in a more sustainable manner. For example,

participant 15, a financial services employee, described returning to his job after a long illness:

> There was a two year delay there while I was on long term
> disability. I recently returned back in the end of November, on a
> gradual return. I'm still kind of under the gradual return. I work
> three full days a week now instead of five days a week. And bi-
> weekly, I guess, we increase another half day. So it's going to be a
> five day work week and it probably will be full time, I think, by
> June.

Participant 5, also a financial services employee, recalled a similar experience; one that increased

her confidence and sense of trust in her employer:

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> When I was off for surgery there were intermediaries contacting me asking, "How are you doing? How is the recovery? When are you coming back?" And it was a modified work schedule thereafter, so if anything were to come up I know that my employer would work with me to bring me back in a small incremental time stage if necessary.

In both these cases, participants worked for large private sector employers who would likely have been in a better financial position in which to afford a supportive accommodation such as facilitated adjustment. Since a large number of participants received no sick leave entitlements as part of their employment, and others had not experienced lengthy episodes of illness, very few reported benefiting from such a program. Nevertheless, these accommodations were well received by the participants who benefited from them and it assisted them in meeting the challenges associated with the adjustment to full time work.

Thus, workplace accommodations were an important vocational structure that assisted study participants in sustaining successful employment. In particular, flexible hours, facilitated adjustment to the workplace following an illness, and a change in responsibilities were common accommodations sought by many study participants.

7.3.3 Workplace Benefits and Policies

Workplace benefits and supportive workplace policies were reported by many study participants as important in structuring a supportive and accommodating workplace and in assisting them to maintain successful employment. As discussed earlier, access to a range of workplace benefits and prescription and medical coverage was an important motivation to work for many participants. When asked about the benefits coverage that was provided by their employer, participants identified a range of prescription, medical, and other supplemental forms of coverage. Some study participants received comprehensive benefits as part of their

employment contract while others identified working in very vulnerable conditions with inadequate coverage or no benefits of any kind. Due to the nature of living with an episodic illness, discussion about employment related health benefits dominated participant narratives. Specifically, participants discussed the importance of accessing essential health coverage, sick leave provisions and the need for supportive workplace policies.

7.3.3.1 Workplace Benefits: a Summary

Before describing participants' experiences with employment benefits and workplace policies, a brief summary of participants' health benefits coverage will be provided in order to set the context (see figure 7.1). Seventeen participants (55%) reported receiving no health benefits through their employer. Of these, 13 were receiving supplemental health benefits through public benefits providers while simultaneously working. The majority of these participants (11) were residing in Ontario and receiving transitional health benefits through the Ontario Drug Benefit Plan (ODBP) as part of temporary return to work measures implemented as part of the Ontario Disability Support Program (Stapleton & Tweddle, 2008). One of two social assistance programs in Ontario, the Ontario Disability Support Program provides long-term assistance for persons with substantial physical or mental disabilities (Lightman & Vick, 2010). Four Ontario residents were receiving prescription benefits through the Trillium Drug Program. The Trillium program is an income tested, catastrophic drug program delivered by the Ontario Ministry of Health and Long-Term Care that financially assists people (social assistance recipients are not eligible) who have high prescription drug costs in relation to their net income (Stapleton & Tweddle, 2008). Most participants in British Columbia and Alberta were in full time positions that provided health benefits. However, two participants weren't in this position, both of whom lived in British Columbia. They reported receiving general health benefits through

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a Medical Services Plan (BC.M.S.P) provided for by British Columbia's Employment and

Assistance for Persons with Disabilities Program and free HIV drugs through a supplemental

program (Stapleton & Tweddle, 2008).

Fourteen participants (45%) from among all provincial jurisdictions reported receiving

comprehensive benefits as part of the employment contract with their employer; all of whom

were engaged in full time or close to full time work (>.8 f.t.e). In all cases, this included

prescription drug coverage including coverage for HIV medication, although several participants

acknowledged only receiving 75% or 80% coverage (a possible issue due to the extremely high

costs of HIV medication). Benefits coverage for these 14 participants also tended to include

standard sick leave and vacation time. A minority of these participants reported receiving support

from a broad combination of other benefits including employee assistance plans, pension

benefits, life insurance, and dental care.

Figure 7.1 Health Benefits Coverage
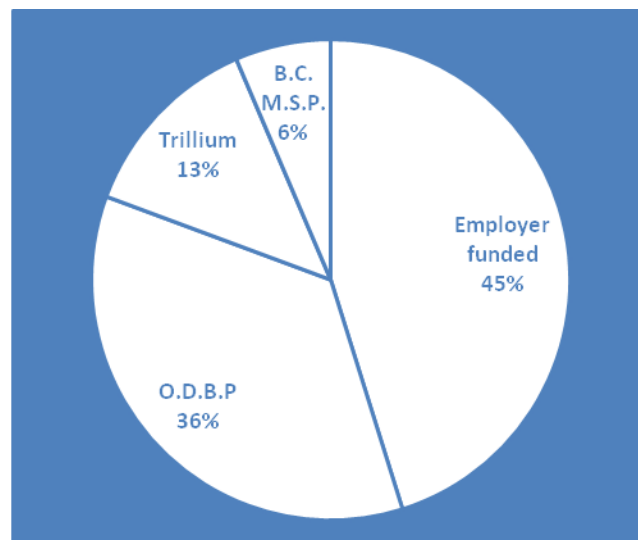
<u>7.3.3.2 Accessing Essential Coverage</u>

In addition to identifying the level of health coverage they received, participants

described their experiences accessing needed coverage. Despite being in the minority, private

sector medical coverage, long term disability group insurance, and pension plans were all

reported as sought after benefits that enhanced participant's ability to remain working

successfully. For those who had access to benefits at work, the coverage reportedly provided an

important measure of security. This was the case for participant 25 who was working in health

and social services:

> I make over 20 dollars an hour and I have great benefits. I have a
> pension; I never thought I would have a pension before… I
> contribute to a union, I also have disability insurance. I am covered
> as a person with preexisting conditions. If I were to take ill I would
> be covered in my work place, which was also important to me
> when seeking where I wanted to be involved. If something were
> ever to change I would want to have that security in place.

For participant 5, having some level of employer provided medical coverage (even if less than

comprehensive) meant peace of mind in the event she becomes ill:

> If I need any antibiotics or healthcare - it's covered. So that's a
> peace of mind for me because if I had to be without anything that
> would be very dismal… Insurance coverage is the biggest element
> of success for having a job.

Participant 19 described the comprehensive benefits he received at his job in health and social

services, a factor that had contributed to an increase in his quality of life after years of living

close to the street and dealing with an addiction:

> Oh God, I am so scared, I have been here a year and a half I have
> not read the whole booklet yet. I get massages, dental; a lot of
> dental, so much dental I have pulled out all my back teeth… I am
> exercising, going to the doctors, I have life insurance, I have
> RSP's, and I have lieu days, professional development days. I have

not worked for so long. If I had been working all these years, this
is where I should have been at now.

Participant 29 acknowledged that even though he did not find his salary particularly attractive,

the benefits of the job provided a broad range of protection and security. He stated, "Yeah. I

mean the pay isn't the greatest… but the benefits are good. The medical is really good;

prescription drugs are paid 100%... The benefits themselves are fine and that you don't see much

anymore."

Despite having access to employer benefits programs, some participants reported still

feeling vulnerable. Participant 23, a manager in a private sector company, described his fear of

having to rely on his employer's short term disability provisions which he felt were inadequate.

He explained, "We have long-term disability but no short-term disability. So EI [employment

insurance] would basically be the option, which is not a lot. I mean I think the maximum is based

at about $28,000 a year." For those participants who had experience with public benefits

providers, private sector packages were sometimes viewed as less comprehensive and a possible

barrier to working successfully. Participant 14, a financial services employee, reported that the

benefits available to him in his full time job were inadequate and that he continued to rely on

medical benefits grandfathered through the Ontario Disability Support Program:

> *Interviewer:* your prescription coverage is still through ODSP?
>
> *Participant:* Yes.
>
> *Interviewer*: Any other benefits through ODSP?
>
> *Participant*: No. Not that I use a lot really. Um, eyewear. That
> would be it. But other than that, no I haven't. And [the
> employer's] package is the bare minimum. There's nothing there.

This was also the case for participant 1, a full time employee in a government department. He described scrambling to find supplemental coverage to cover the 20% of medication costs not covered by his employer's benefits plan:

> They will cover 80 per cent of my prescription costs, up to an annual total prescription amount of $15,000 and then they will cover 100%. Until that point though, my out-of-pocket monthly expense for my HIV alone is $650. And that is a crime... when they can send all these meds to other countries or they can find alternatives to do what they can do with meds, but I find myself having to pay $650 a month, and that's regardless of what my income is.

As discussed earlier, many participants reported being scared to disclose their HIV status and were worried about means testing in order to receive employment-related health benefits. However, those who were fortunate enough to have workplace benefits coverage did not identify any barriers to accessing these benefits programs as a person living with HIV. When asked if they had problems accessing their employers' benefits plans, several participants replied that they were automatically added to the plans with few questions. This was the case for participant 29, a gay male working in the hospitality industry. He indicated, "No it's automatic…the benefits are very good. Like I said, the pay is not the greatest, but the benefits are pretty iron clad." This was reiterated by participant 21, an AIDS service organization employee:

> I think the policies here are that you don't need to disclose anything. You have to fill out the papers and everything. Once you get the response, you need to report it to human recourses or administration, and they did not ask anything.

Participant 3, a gay male working in transportation, reported a three month waiting period prior to being added to the company benefit plan; this was a period where he felt very vulnerable:

> When you sign up it is within the first 3 months. If you do not have any episode of illness then you are covered… I was like, "Oh good

I am covered now." I am curious to know if the insurance company
would be supportive nowadays.

7.3.3.3 Sick Leave

Receiving adequate sick leave as part of formal workplace policies was seen as very

important given that participants were all dealing with the vulnerabilities of an episodic illness.

Study participants identified access to adequate leave as critical to their vocational goals, and a

wide range of experiences in this regard were reported. Unfortunately, many participants

reported working in very vulnerable conditions with inadequate coverage or no benefits of any

kind. As mentioned, in most cases supplemental medical benefits were provided through

provincial income support programs. Nevertheless, 13 participants reported receiving no paid

sick leave entitlement as part of their employment; a critical lack of coverage for vulnerable

individuals with episodic health conditions. These participants were more likely to be in

precarious employment situations and were more likely to be women or from visible minority

groups.

Nine of the 13 participants reporting no sick leave were engaged in part time, contract or

temporary work. Additionally, study participants from marginalized populations were more

likely to be working with no sick leave coverage. For instance, three women in the sample, one

transgendered participant, and eight participants from visible minority groups were in jobs that

provided no sick leave benefits. Consequently, if they were sick and unable to work, they did not

get paid, a situation that contributed to job loss and cycling in and out of employment. As

discussed in a previous chapter, many participants felt a pressure to work even if they were not

well. Participant 16, a full time waiter, described the pressure he felt to not go home sick when

working in such an environment:

In a restaurant there are no sick days. If you call in sick or just go home sick, unfortunately you lose like a lot of money because it's not just your hours but it's your ability to make gratuities. So, in that respect, you know you can go home sick or whatever, that's fine, but it's not in your best interests. So, kind of a bad. You know, sometimes I, I try to fight it. And a lot of servers do. Because they know if you go home sick, there's no sick day, there's no nothing.

Participant 10, a recent immigrant and a single mother, worked part time for a residential cleaning company that provided no benefits, sick leave, or break time. She described what this was like:

Interviewer: So if you are sick at the cleaning job you don't get paid?

Participant: No, she calls and says, "Can you come in? Can you come in"? I said, "I am sick, how can I work"? So I don't get paid.

Interviewer: No sick leave of any type?

Participant: No.

Interviewer: No vacation?

Participant: No, you don't get paid. And no lunch, we eat in the car. We work 9 hours nonstop. We eat in the car.

Interviewer: It must be hard to work 9 hours straight without a break?

Participant: Sometimes me and my work partner we have to take a break in the houses, we sit, but she knows how many hours it takes to clean the house.

Participant 11, a gay male from a visible minority group, working part time for an AIDS service organization, described working in a similar situation with no benefits save vacation pay:

Participant: No. The only benefit you get is the vacation pay. That is included with each paycheque.

Interviewer: If you are sick and cannot work, you don't get paid?

> *Participant*: You don't get paid. And you are also somewhat
> responsible to find coverage yourself.

Participant 18 also worked part time doing outreach for an AIDS service organization that

unfortunately provided no sick leave benefits:

> There were some times when I had a cold and I couldn't go in, or
> times when it was a cold blizzard, or extremely rainy out. We don't
> get paid unless we go. I have not missed work in a long time.

Participant 13 worked two part time jobs, one of which was for a faith-based organization.

Unfortunately both employers provided no form of benefits:

> *Participant*: I'm actually on contract so with my [employer]. Even
> though it's a regular paid position, I'm not considered a regular,
> like a full time employee, so don't get the benefits that a full time
> employee would get.

These experiences were in contrast to those in professional roles who were more likely to receive

better leave provisions. Participant 27, a highly educated professional described having more

leave time than he could handle:

> We have a whole bunch of sick days which I have never used in
> four years. I have not missed one [day of work] apart from a
> conference, but I found a replacement. Even if I was sick, I would
> just call in sick, it is not a big deal at all.

Participant 5, a financial services employee, acknowledged explicitly that the leave provisions

she enjoyed were attributed to her role as a professional:

> We get family day off, we get Remembrance Day off. We only
> work Monday to Friday during the course of normal business hours
> 8 to 4. So I have other flexibilities to live a life outside of that. I
> have my weekends, and my 3 week holidays, sick days if
> necessary, right, the kind of benefits that come with the
> professional role.

Consequently, receiving adequate sick leave was described as very important when dealing with

the vulnerabilities of an episodic illness. Study participants identified access to adequate leave as

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critical to their vocational goals and a wide range of experiences in this regard were reported

including a high number of participants in precarious employment situations with little access to

adequate sick leave policies.

<u>7.3.3.4 Workplace Policies</u>

In addition to workplace health benefits, workplace policies were identified by some

participants as playing an important role in structuring supportive and respectful workplaces. In

several cases this included policies that allow for the special needs and contributions that people

living with HIV present in the workplace. Participant 6, a single mother working for an AIDS

service organization acknowledged that in general a supportive policy structure was important,

but not necessarily done with forethought on the part of some employers:

> But a PHA [person living with HIV] doesn't come as this complete
> package, just like anybody. And then when we throw them into
> these jobs, what systems are we putting in place to support them?
> So, like, I always say, "Do you want to hire me because I am a
> PHA? But I come with these limitations. Immediately, when you
> hire me, what are you putting in place"? So, that's, that's a huge,
> huge challenge that I see.

Echoing this, participant 8, a financial services employee indicated his preference for working

for employers who have respectful policies in place:

> The companies that I would want to work for are the top fifty
> companies that handle employees the best. So, that's the
> companies I'd like to work for. Okay, having been through all this.
> That's because they treat you with respect. And they understand
> that taking care of the employee is taking care of the company. It's
> really simplistic.

Additionally, participant 14, also a financial services employee, acknowledged that policies

fostering inclusivity and equity had been important in his securing employment:

> When I applied for the job there.... on the application forms it asked, "Are you an individual with a disability"? And you clicked that.... They don't want to know what your disability is, but if they do ask then you do need a note from your doctor stating that you are disabled… I think that actually got me in a lot quicker, because at that time it was very hard. It was difficult when I started looking for jobs to answer why I had taken that time off.

Gay men are still disproportionally affected by HIV when compared to other populations. Thus inclusive workplace policies that addressed homophobia and heterosexist assumptions were seen as important. This was acknowledged by participant 22, a full time employee working in health and social services, who described the importance of flexible policies:

> What makes me enjoy being here is an understanding of the, not the homosexual, but the nontraditional family. So, like, if my lover's mother was sick I couldn't take family time to leave. They didn't recognize my partner as my partner. But here they allow me to determine who my family is. So if it's my best friend's mother, I can count that as a family thing,

Thus, workplace benefits and supportive workplace policies were reported by many study participants as important institutional factors that assisted them to maintain successful employment.

7.3.4 Dealing with Workplace Stigma and Discrimination

In addition to other factors, dealing with workplace stigma and discrimination were described by some participants as a prominent feature of their employment experiences. HIV stigma, homophobia, sexism, and racism were workplace challenges experienced by several participants. These experiences hampered participants' vocational success and created fear and stress as they moved to new vocational settings.

Several participants reported the stigma and discrimination that has long surrounded HIV as present in their workplace and negatively impacting their employment experiences. Participant 30, a long time survivor, recalled losing his job early in the epidemic:

> Back then there was a lot of fear. It's funny; I felt it hurt me as far as my career. I also was teaching part time and I lost my teaching job all of a sudden even though I was getting really good references. I was teaching all around the province and all of a sudden I got this phone call saying, "We are going to have to let you go."… I had a feeling I was let go because of my HIV status. They wanted to get rid of me before I go on any disability. It was a big international company I was working for. It really soured me.

Unfortunately, such experiences were not just vestiges of the past. Other participants reported leaving more recent jobs due to experiences of stigma and discrimination. Participant 5, a recent immigrant, reported quitting two successive jobs due to workplace stigma and discrimination. In the first example, she described leaving her position as a supply teacher after her HIV status become known in the community:

> But when you walk into a classroom and kids walk out, you know, and parents tell you, "My child will not come to be taught by an HIV positive person and I'll keep them away from school until the school does something." You see that, you know, the principal wants you, but, it's not up to the principal. Right. So, ya. Not a dream job. That's, that's part of loss, right.

Next she described a similar experience when working in the private sector:

> I started noticing people were no longer using the office bathroom, and there were suggestions that.... We used to wear white coats and then there was this suggestion that they should be, we should have our names on all coats. And, you know, a lot of things played out. And, then, the fifth day, I just didn't come back. So, ya, it's, a challenge.

Participant 1 had also witnessed a colleague who was systematically harassed in the workplace, an experience that left him feeling helpless and fearful:

For example, we had one manager, who, they had no sympathy,
empathy, anything whatsoever for anyone, regardless of what the
handicap, illness, disability was. This person was out for their own
name, agenda and whatnot, and there was a person who did have
AIDS, and they were just driven out. All we could do was watch.
If anyone said anything, we'd be next. The individual ended up
being hospitalized and passed away. It was almost cruel. I think it
is cruel. What ended up happening? I ended up having to go on
leave.

In addition to HIV stigma, other forms of workplace harassment and discrimination were

reported. Several gay men discussed the homophobia they had encountered at work. For instance

participant 20 described his attempts in being discreet to protect against the kind of

discrimination he had encountered in a previous workplace:

Well I don't wave flags… You won't find me wearing kind of
weird dress attire to work. You won't see the gay flag on my desk.
I try to be, well I think that I had my lessons back in [previous
employment]. One of the positions I had was with the
governmental offices, and I had to go through a clearance process.
I had lots of nasty questions about being gay. Even though I had a
boy friend, I felt that there was huge discrimination about it.

Participant 26 also described leaving an earlier job due to the homophobic environment:

So at the time I was diagnosed, and it was with an AIDS diagnosis,
and I was working in a role that was not a nonprofit organization.
It was a very corporate sporting venue, pretty homophobic on a
regular basis… I certainly did not feel comfortable disclosing to
my employer at the time, this was like 16 years ago. So I left to
take care of my health.

In many cases, the effects of these stigmatizing experiences lingered with individuals and caused

them fear, even in more supportive workplaces. For example, participant 12 described being

fired from an earlier job due to homophobia; an experience he carried into other vocational

settings. He recalled, "Even though I worked for the same hotel for so many years, when my

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boss found out I was gay, she tried to get rid of me… She almost killed me, when she knew I was gay."

In addition to homophobia, participants described sexism and racism as workplace factors that impacted their success. Participant 6, an immigrant working in an AIDS service organization, described the challenges she faced when dealing with the effects of sexism and racism in her workplace:

> When you work in a specific ASO, the internal challenges can really be dramatic. You find that within our own community there are bouts of discrimination. So, sometimes you deal with being an African versus being Caribbean. Sometimes you deal with having kinky hair versus having..... So, we do deal with that every day and we are working towards that, but it's, more hurtful if it comes from people that you think you identify with. Right. And also in the HIV field … having to always prove yourself as a woman, at a table that can be dominated by men. And also that you come with a brain, not only cleavage, OK .... I do experience that a lot.

Additionally, participant 15 suspected that racism was a discriminatory feature of the hiring practices in his industry.

> There are very nice people there, and other people they are not. Discrimination in the old Canadian way. They discriminate against the Indians… one company I know they did not give me the job because everybody in the company was Chinese. I applied and had an interview; I knew they would not give me the job, everyone was Chinese. It is true, I felt that way.

Many participants affected by workplace stigma and discrimination were able to find more supportive environments. Nevertheless, dealing with HIV stigma, homophobia, racism, and sexism in the workplace were experiences that created negative impacts for these individuals and influenced their future employment.

7.3.5 Workplace Barriers faced by Immigrants

A distinct set of institutional barriers were reported by study participants who were also recent immigrants to Canada. In addition to facing racism and discrimination, several participants reported language barriers and the failure of Canadian employers to recognize their experience and credentials as workplace issues. These issues often jeopardised participants' employment trajectories and made it more difficult for them to be successful in the workplace.

Several participants, who were also immigrants, described issues related to their credentials not being accepted in Canada; barriers that often meant they were relegated to precarious employment situations. These participants reported going through lengthy training and certification processes and still found it difficult to find employment in Canada. For instance, participant 23, a European immigrant, described retraining after arriving in Canada:

> When I came to Canada as an in immigrant I had a financial analyst background, but I couldn't get a job in banking because I didn't have any Canadian experience… So I basically worked my way through workshops. I've got about three out of four years of postsecondary education, but I don't have a formal degree. I worked through the various processes to get into the companies I got into basically. I always say the University of hard knocks was my kind of degree.

Participant 21, an immigrant from the Middle East, described having to re-certify despite extensive experience in a similar position in his home country:

> Since I arrived in Canada, in November 2008, I had a course I was taking to convert my credentials to Canadian ones. I will be ready for the Canadian market, even though quality assurance is quality assurance all over the world: same standards, same rules, regulations, everything. Still there are some differences between cultures and workplace habits, things that are accepted are not acceptable all over. I took this course. Still I could not find a job. It took quite a long time after that one.

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This was also the case for participant 21 who felt as though he needed to start all over again after arriving in Canada:

> It was hard to start all over again; going through all those processes again, of accepting my credentials. My mind was not really into going through all the process. I definitely started over again with a combination of training, studies, and work experiences.

In addition to having to retrain and re-certify, several participants who were also immigrants reporting struggling with language barriers. Participant 20, despite being in Canada for many years still reported language as an employment barrier. He explained, "I think related to HIV status was the lack of experience, and a language barrier. I still find myself struggling to be more fluent in English, to express myself in better ways, especially verbally." For some, the combined impact of language barriers and not having their experience or credentials recognized meant they were relegated to difficult jobs working in precarious situations. This was especially true for women and those who were recent immigrants from developing countries. For example, participant 4 and participant 10 were both single mothers, both recent immigrants from east and central Africa, and both reported working in demanding and low paying jobs, with no benefits and inadequate sick leave. Participant 4 attributed language barriers and not having her skills recognized as barriers keeping her from realizing her vocational objectives:

> My experience and training was not recognized in Canada. Here it is really different… I know that my big barrier is English; that is the big one, writing in English, talking in English. I have a heavy tongue. It is not easy. It is the only problem I have right now. AIDS and English are my barriers.

Despite being trained in retail in her home country, she was working part time as an office cleaner. Although she found the job physically demanding, she also hoped it would help her gain Canadian work experience:

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> In that job it was really hard because I had to clean five floors; five floors in 5 hours. I have to clean five floors and they are big. I have to take the garbage, you have to dust, you have to vacuum… For me this is really good because as the newcomer you have to learn to get more experience. So if they look at your resume you can answer their questions.

Participant four offered a similar narrative. Also a recent immigrant, she described language barriers and the refusal to recognize her credentials as barriers. Thus, she working in a cleaning job rather than in the administrative role she was trained for in her home country. She also described the physical labour as difficult, given her illness:

> I find housekeeping is too hard for me, it is physical… I loved my researching job because that's what I was doing back home. Working for the federal government; I was a secretary. When I came here the English is different.

In sum, two specific institutional barriers reported by study participants who were also recent immigrants were language barriers and the failure of Canadian employers to recognize their experience and credentials. These issues jeopardised participants' employment trajectories regardless of country of origin or length of time in Canada. Nevertheless, women and those who had immigrated from a developing country reported more difficulties in overcoming these barriers.

This section described the category of work, a major component in this conceptual framework. In summary, participants identified workplace environments, workplace accommodations, workplace policies and benefits, dealing with workplace stigma and discrimination, and workplace barriers faced by immigrants as important institutional factors that shaped their success in the workplace.

7.4 Community

A foundational idea in sociology, social work, and public health, the concept of community has also historically served as an important factor in the life of the response to the Canadian AIDS epidemic (Silversides, 2003). Citing the health promotion literature, McElroy et. al. (1988) acknowledge that community may be defined in a variety of ways including, "… a psychological sense of community, a political entity, a functional spatial unit meeting sustenance needs, a unit of patterned interaction, or simply an aggregate of individuals in a geographic location" (p.363). In ecological frameworks, community is understood as a major source through which political, social, and economic forces exert influence on individuals' lives, and as mediating structures that serve as connections between individuals and the larger social environment (Gitterman & Germain, 2008; McLeroy et al., 1988). Thus, it is through community engagement that individuals are most likely to connect with support, find purpose, solve problems, and increase health (Saleebey, 2001). Community factors may influence an individual's values, beliefs, attitudes, and behaviours while simultaneously serving as a means of support and playing a role in defining community health issues (Maton, 2000). Not restricted to the existence of specific organizations, influences at the community level may also include concepts related to community political and power structures as well as community interventions such as increasing access to community resources, organizing strategies, and coordination between organizations (McLeroy et al., 1988). Community structures were described by many participants as an important and effective bridge to employment. In particular, study participants described a set of community structures that specifically influenced labour force participation, notably AIDS service organizations and vocational services. This section describes the fifth major category in the framework, community and its related subcategories.

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7.4.1 AIDS Service Organizations

The concept of community resonated strongly with study participants, many of whom expressed a desire to connect with and contribute to the broader community and the AIDS movement. The general importance of community was expressed by participant 19, a gay male working full time in health and social services who suggested that, "Community is important for people in the world of HIV… it feels like I am part of the community, and I have made something for me." This was also confirmed by participant 31, a long time survivor of HIV, who discussed the mediating effects of community involvement:

> I think it's really important to have a really good social network,
> both family and friends, and also for me in terms of being involved
> with the HIV community… staying connected with my community
> so that I am not alone living with this disease.

A common route to community participation was through involvement with AIDS service organizations. Existing in many Canadian municipalities, these grass roots organizations tend to provide AIDS education, prevention, and care and have increasingly sought to involve community members and people living with HIV in the response to the disease (Ontario AIDS Network, 2011). The programs, networks, and initiatives organized and delivered by these community-based organizations were described by study participants as important in mediating vocational barriers and facilitating sustainable employment. The range of support services offered by AIDS service organizations were extensive and ranged from practical supports to initiatives designed to empower people living with HIV and assist them in participating in the broader AIDS movement. Subsequently, study participants reported engaging with AIDS service organizations in a variety of ways including accessing services, connecting with peers, participating in leadership training, and through paid employment. Consequently, for many

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participants, AIDS service organizations served as a bridge to increased community involvement and as a path to employment.

7.4.1.1 Accessing Services from AIDS Service Organizations

Many participants acknowledged using AIDS service organizations for support on a wide range of issues including peer support, information, food security, and financial assistance. While a few participants acknowledged accessing AIDS service organizations for emotional support and counselling, it was practical assistance and peer supports that were most frequently discussed and were widely reported as being closely connected to assisting in successful employment. These supports were seen as supporting their vocational goals by helping them meet needs that they could not adequately meet solely with income from employment.

Despite working and receiving extra income, close to one third of study participants reported still facing financial vulnerabilities and relying on AIDS service organizations for financial assistance programs and food banks to assist them to make ends meet. This was particularly true for those in precarious employment and those from visible minority populations. Individuals from these groups were more likely to be part of the working poor and often depended on supplemental supports. Of the ten participants who reported accessing either food banks or financial assistance programs, five were from visible minority population groups or had recently immigrated to Canada, and six were engaged in part time or contract work with few benefits. Two female participants reported accessing practical supports. While the other three women in the sample reported facing economic difficulties, they were less likely to be connected to an AIDS service organization and reported getting support from extended family members or those in their cultural communities.

Community-based AIDS service organizations were frequently mentioned as the most common source for practical supports and their financial assistance and food security programs were relied on by many participants. Participant 1 emphasized the vocational importance of such programs, "The support services are very crucial to job maintenance. It really is crucial and if they don't have that, if that falls apart than any other illnesses, like mental health will kick in, not will - can. I think that's really important." Participant 18, discussed how practical and outreach services, organized by AIDS service organizations, were vital to his health during an episode of illness. He explained, "A couple years ago I had pneumonia. They helped me get food bank, they drove me to the doctor, the food bank, and they would drive me to the grocery store. They would really come in and help you." Participant 16, a full time waiter, reported using financial assistance programs to fund health care needs not covered through his employer:

> I also do use financial support from [AIDS service organization]
> and they're a great group, they absolutely are. They really helped
> to cover the other things that are really expensive that pop up, like
> massage therapy, or dental care.

Although participant 5 received health benefits through her full time job at a financial services company, she still reported relying on AIDS service organizations for supplemental and complementary health care:

> I get supplements and even my own health care benefits don't
> cover it. I need supplements to keep my cholesterol lower and to
> help my molecular cells and all that to keep them rebuilt. [AIDS
> service organization] gives me a certain amount of that up to a
> maximum ceiling so it's a really good resource for me to have to
> keep myself as healthy as possible.

Several participants reported accessing food banks as a means of supplementing inadequate employment income. Participant 11, a part time employee at an AIDS service organization acknowledged accessing both financial assistance and the food bank out of financial need. He

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explained, "There are times when I have to access the food bank there or I have to access financial assistance, because even though I am working there, sometimes it is not enough." The food bank was also described by participant 15, a full time labourer and recent immigrant, as a valuable support:

> They give some food. Because I live alone it helps me lots so I
> don't need to cook too much. I take that program maybe every two
> or three months. I take the food bank. I need the food bank.

Participant 14, a full time financial services employee reported using the food bank at his local AIDS service organization for health reasons, and out of financial need:

> The food bank, I use that quite often actually… I am very sensitive
> to a lot of things. To buy generic foods, I would become sick…
> That's why I dropped a lot in my weight, because I couldn't
> afford.... I can't buy frozen lasagna, let's say, I have to make it.
> And to make full lasagna, it could cost you fifty, sixty dollars.
> That would be my groceries for two weeks. I can't take a lot of
> things with a lot of preservatives, I get terrible heartburn, I actually
> violently get ill… to the point where my health becomes
> detrimental. My doctor actually was going to admit me to hospital
> because I wasn't eating. So there wasn't enough money to provide
> for me, for proper nutrition

Participant 5 indicated her reluctance to use the food bank but acknowledged that at times it was essential:

> If I'm short and I don't have any groceries they have the [food
> bank]. You can go once every Monday, every two weeks or
> whatever. I like that type of stuff and because there's no cost
> involved it's my middle name – free. So I'm in there and I
> participate in that regard… I consider myself pretty proud; I don't
> utilize those services unless I'm in dire need.

Thus, these supplemental programs organized by AIDS service organizations helped support participants in employment and acted as a buffer against poverty.

In addition to practical assistance, peer support programs were described by several participants as useful community services offered by AIDS service organizations. Many participants wanted to connect and gain support from other people living with HIV who were experiencing similar challenges. Participant 31 summed up the value of peer support programs, stating, "I needed a lot of support and I needed to be reaching out to my community and feeling connected to my community." Participant 16, a gay man, described drawing support through hearing from others who have been in a similar situation:

> I definitely have used services here at [AIDS service organization].
> Not so much for scheduled counselling but more just to drop in and
> have just a conversation with somebody. Cuz a lot of times those
> talks with somebody who's been there and done that really helped.

Participant 5, a single mother, explained how a peer retreat and social media facilitated supportive connections with other women living with HIV:

> I made good close friends during those retreats. Facebook's
> allowed me to maintain the communication with them because
> they were my support during the first couple of years of this
> illness. They really really helped me, and they are the long time old
> timers that have come so far, and are here breathing, and give me
> the strength to say, "Okay, it's not that big of a deal." … Yeah,
> they really helped me through my questions because sometimes
> something will get thrown at me and I'll need to know how to cope
> with that and they're the ones that have already come through it.

Additionally, participant 24 described how accessing the food bank progressed to gaining community support through peers:

> It's really important to me to have people to talk to about this… it
> is important for me to be connected. I don't meet HIV-positive
> people unless I go out of my way to meet them … I came here to
> [AIDS service organization] and started picking up the [food
> hamper] and there was sort of a progression of things and then I
> met people and they suggested other peer services.

In this manner, peer support, facilitated by AIDS service organizations, proved to be important general supports for many participants. They were also specifically discussed in relation to vocational service provision, an important factor that will be described in fuller detail later in this chapter.

Accessing practical services and peer support was not the only way in which participants described connecting with AIDS service organizations and their broader communities. Working from an empowerment model, some AIDS service organizations reportedly supplemented service provision with leadership training and capacity building programs for people living with HIV. Often provided as part of participant retreats, these regional initiatives offered in partnership with AIDS service organizations aimed to assist people living with HIV to develop leadership skills, and to gain community knowledge and awareness. Many study participants described these initiatives as important bridges to fuller participation in the community AIDS movement and subsequent employment. For example, participant 17, a gay male working in health and social services recalled how participation in a regional leadership program offered by an AIDS service organization assisted him in improving and developing employable skills:

> I did the HIV positive leadership program through the [AIDS
> service organization]. I found this to be a very good program that
> helped prepare me for employment and helped me develop
> leadership skills and to understand that leadership can take many
> forms.

Participant 28 credited participation in a similar community leadership program as facilitating his transition towards a new role within full time employment.

> While I was doing that retreat I had something called the leap of
> faith, where you climb up a pole, and you're harnessed in, and you
> are tethered to the ground. You have people holding the rope on
> the ground, and you are anchored, and there is this bar, like a
> trapeze bar. So you have to jump off the platform to grab the

trapeze. Literally my thoughts were, "If I grab this I am meant to
go back to work", that was the thought in my head. It was scary. I
jumped out, and I am a bit top heavy you know, and grabbed it,
and I slipped and fell… All of a sudden I felt this huge support
because I am tethered in right? I am on a harness and I look down
below and there was like 3 people down there and they are all
holding it and I went, "It's not that I didn't try." It sucked that I
tried and failed, but it was the fact that there is support. I was like
go for it, you created support in your life, you can access support,
you can look for things, it was about trying it, just try it. So that
was an incredible "uh-huh" moment for me that I needed to learn,
and it enabled me to kind of go forward with employment.

Participant 31, a gay male employed in health and social services, described how a leadership

development retreat assisted him to connect with his community and find a balance with his

work life:

Last year I did [AIDS service organization] retreat which I found
very beneficial in terms of providing food for my soul, and
understanding that it's very easy to get into a rut just working and
sleeping and eating and working out, and not really paying a whole
lot of attention to life and what it means, and challenging yourself
to get out side of that comfort zone… So after that retreat I have
volunteered to volunteer with them. I find it useful as a balance
with my work life, that I am giving back to my community using
my skills that I have from my work life and using that in my
community and continuing to feed my soul.

Several participants explicitly linked leadership development and capacity building to their

success in employment. For instance, participant 12, a gay male in the hospitality industry

acknowledged how participation in AIDS service organization training initiatives were preparing

him for a new vocational role and possible full time employment:

All the trainings I have been having now so far, I am graduating at
peer counselling. All that stuff can help me a lot at work, and to get
a new job. I think I am prepared now… I think I am 100%
prepared to have a full time job.

Additionally, participant 24 discussed how leadership training had led her to consider

employment in the AIDS sector remarking, "I just got back from the [leadership program] last

weekend. It was fabulous. I'm hoping to, in fact, I wouldn't mind working in the ASO

community, so maybe someday I will." Participant 28 also recalled being inspired to get more

involved in the community as a result of his involvement in leadership training:

> It was only from my training with the [AIDS service organization.
> It is so much more meaningful for me now. Like when I heard of
> [leadership training program]… it was more like the feeling of I
> am going away to something free to get away and kind of think.
> And because now I know what work can be accomplished, and I
> can be involved in, and be witness to, I am looking forward to see
> what that might be.

Consequently, leadership and capacity building programs were important programs that provided

an additional layer of involvement in community AIDS service organizations while

simultaneously supporting study participants' vocational goals. While not explicitly developed as

vocational interventions, practical supports, peer support, and leadership development programs

delivered by AIDS service organizations assisted many participants in maintaining successful

employment.

7.4.1.2 Volunteering in an AIDS Service Organization

As discussed earlier, many participants reported a desire for meaningful work and

opportunities to reinvent themselves following their HIV diagnosis. Several participants sought

these experiences by contributing to their communities and volunteering with their local AIDS

service organization. Almost half of study participants, the majority of them gay men, reported

volunteering in the community and within local or provincial AIDS service organizations. Many

of them did so out of a desire to connect with others in the community. For these participants,

volunteering was a manageable route to explore their employment options and several described

developing skills that assisted them in securing sustainable employment. As participant 19, a community activist explained, many people are "thrilled to get involved on a one-on-one level, and to give back to community." This was certainly the case for participant 31, a gay man who had been living with HIV for many years, who volunteered in addition to his full time job:

> I find it useful as a balance with my work like. I am giving back to my community, using my skills that I have from my work life and using that in my community and continuing to feed my soul.

Additionally, many of these participants described their volunteer experiences as supportive of their vocational goals and as a successful route to paid employment. This was the case for participant 11, a gay man experiencing a career transition. He recalled how volunteering in his local AIDS service organization had helped prepare him for employment in a new position:

> I think the ASOs I have worked with as a client have been quite supportive and helpful in keeping me busy and keeping my skills current. So when I present to a new employer it is not like I have been out for 18 months and done nothing. I have been involved in the community, health fairs, and volunteer positions.

Participant 17, a full time employee in an AIDS service organization, described how his volunteer experiences assisted him in finding his current position:

> During the four years when I was working and in the last two years of that I started volunteering. So I was volunteering for an [AIDS service organization] and that's how I reintegrated back into work. I created a job in the program and became indispensable.

Participant 23, a manager in a private sector company, described a similar transition explaining that, "I kind of worked myself into a job. I volunteered and I thought, 'oh I can do some of this,' so I actually volunteered with them for a month and they started paying me after a week." This was also the case for participant 18:

> I started doing some volunteer work with [AIDS service organization]. I started public speaking, and volunteering, and doing some admin work. Going out to … communities, and other cities, speaking about my story. Then I started with [current job].

In many cases, flexible policy and governance structures within AIDS service organizations allowed participants to transition from the role of client, to that of volunteer or staff person. Participant 28 described how this flexibility allowed him to contribute in a wide variety of roles:

> I needed to be engaged in community. I was never one not to be engaged. Now I wasn't working, I thought, "Oh I got to do something," so I quickly became involved in [AIDS service organization] and was a volunteer for them for 10 years. I started off slowly, kind of curious about attending the brunch programs… Slowly, at the same time, I got involved in committees and the governance of the organization and I thought, "You know, any time you step into a role that involved committee work and governance you are kind of always opening yourself up,"… which led me actually to being involved on the board of directors… So I just love that idea.

As mentioned, the majority of participants who reported volunteering within AIDS service organizations were gay men. For some, this participation involved a connection to broader based communities as much as it did to the AIDS movement. This was the case for participant 31, a gay male active in several community initiatives. His volunteer involvement in AIDS service organizations predated his own HIV diagnosis, and he reported explicitly wanting to contribute towards the gay community:

> I volunteered here since early 92 or something. So I had the experience volunteering here before I was HIV positive. Here was my community, you know. Times had changed, there were a lot of gay men, I am a gay man, it was sort of helping your community or being part of your community, you know. I like to be involved. I like to be active.

Participant 19, reported a similar motivation, but in this case it was being involved in the

Transgender community that interested him most. He explained, "I like helping out the Trans

community too…. It's just easy to work there. We trust each other."

In sum, volunteering in AIDS service organizations provided meaningful experiences for

many study participants and fulfilled a desire to contribute to the community. In many cases,

these volunteer experiences helped provide a sense of connection, and directly supported

participants' route towards employment.

7.4.1.3 Working in an AIDS Service Organizations

Many participants reported transitioning to full or part time work in AIDS service

organizations as an extension of their community involvement at other levels. Again, as was the

case with volunteering, this was often motivated by a desire for meaningful work and to

contribute to the community. As participant 17 summed up, working in an AIDS service

organization is, "about being involved in the community." Among the study sample, 11

participants reported currently working for an AIDS service organization, several of whom

reported a variety of reasons and benefits associated with this particular vocational choice. For

instance, participant 17, described how his current role at an AIDS service organization generally

fit well with his personal values:

> I've just managed to put myself in contexts where HIV is either a
> nonissue or it works to my advantage… Although the other jobs
> were aligned with my values, this job is more aligned with more of
> my values, and is also aligned with my inherent abilities. It just
> feels more comfortable. I don't have the stress, tightness in the
> chest that I did when I was doing [previous job] and I am just
> much more calm and relaxed; at ease.

Several participants appreciated the non-judgmental atmosphere provided by AIDS service

organizations and work environments that enabled them to be open about their sero status and

sexual orientation. This was in contrast to many workplaces that participants reported as

stigmatizing. For example, participant 22 described feeling comfortable enough in his current job

to openly disclose his HIV status:

> Because this is an HIV agency, I have more freedom to disclose.
> There is no fear of judgment. That's a rarity because of the agency
> I work at. At the one before, any sort of variant in health would be
> frowned upon… Like here they have a greater understanding of
> people with HIV… They understand the weight that people with
> HIV live with. And there is no judgment here, none what so ever.

This was also the case for participant 21 who credited a safe work environment in supporting

him to disclose both his sero status as well as his sexual orientation. He explained. "They are

pretty open with my sexual orientation, with being HIV positive. I am a little bit gay. It is very

easy, and everybody understands." Participant 28 appreciated a workplace that he described as

free of stigma and where HIV was no big deal. He reported, "I have got it easy here… it's just

like who cares, that's kind of my attitude about it. Everybody has a journey in life and on my

journey I have HIV it's just part of the stuff that I have to deal with." Participant 29 also

appreciated an open and non-judgmental workplace. He commented, "There is a comfort level

you know… it is pro gay, and pro HIV positive, pro sex. It was just very supportive."

In addition to lack of stigma, several participants working in AIDS service organizations

reported receiving understanding and support related to their experiences living with HIV.

Participant 10, a recent immigrant summarized this as "more sick time, and more people to talk

with… When you work in an AIDS organization they understand." Participant 6, a single

mother, recalled how she explicitly chose work in an AIDS service organization for this reason:

> It's also funny how it played out, because I ended up getting a full
> time job in the AIDS field. And I geared towards that because I
> was very nervous about the challenges of, you know, my meds. I

wanted to be in an environment where I could be nurtured, and I
could be understood.

This was particularly true regarding support during episodes of illness. A sense of understanding

for the challenges he faced when ill was important to participant 28, a gay male who worked

exclusively for AIDS service organizations following his diagnosis:

> They are very understanding. If I am experiencing any type of
> illness you know I can take time off… I think that's the kind of
> support, they know there will be times you are not feeling well,
> whether it's HIV or just what ever. You have got very
> understanding people. I don't know what other people experience,
> because I have not worked outside of an ASO after my HIV
> diagnosis.

This was also true for participant 11, a gay male who experienced negative reactions in past

workplaces:

> I think if I was to be ill, or sick, or just run down, I think that I
> would get more support in this new situation because they are
> getting other people, some of whom are not well…So I think the
> experience would be quite different.

Participant 22 described what he felt was the difference between working in an AIDS service

organization and other employers:

> It is a calmer and more caring place, so that is a bit different. The
> private sector was driven by the bottom line, and this is driven by
> people. We do pay attention to dollars; we do have to justify our
> stuff to the funders, but the foundation of this business is much
> more about people. The other one was more about money.

For several participants, the opportunity to connect with their peers as co-workers was a

factor that contributed to their choice to work in AIDS service organizations. A sense of

camaraderie contributed to the satisfaction that participant 10 felt in her position. She explained,

"We have someone to talk with... Sometimes we all go for lunch together, we can go and talk

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and do things together. When you need help we work together and support each other." This was

also the case for participant 22 who appreciated the connections he was making with both HIV

positive co-workers and program participants:

> I really like the interactions I have with other HIV positive people.
> Actually, what makes me good at it is my ability to communicate
> with them and I've lived through most of the experiences that most
> of our participants have. We have a shared history and we have a
> shared understanding of life and living so there is a greater ability
> to communicate.

Participant 9, a gay male who was new to his part time job as a researcher in an AIDS service

organization, also appreciated the opportunity to work with his peers:

> Other peoples experience, I am more exposed to that here. I have
> got more information and more sources. I find the two guys I work
> with in [program] they are supportive. All three of us help each
> other around health.

In addition to connecting with and receiving support from their peers, several participants

working in AIDS service organizations reported valuing the opportunity to utilize their life

experiences as people living with HIV on the job. Being in safe and supportive workplace

environments allowed some participants the opportunity to openly disclose their status and

allowed others to benefit from their knowledge and experience of living with HIV. In this

environment, their distinct experiences as people living with HIV were valued as vocational

strengths, assets they wanted to share with their communities. This was eloquently expressed by

participant 19 who asserted, "There needs to be more involvement with PHA's returning to the

work force. We are a valuable resource, we are significant, we can make a significant impact."

This belief was shared by many participants including participant 12, who described his

motivation for working in the community:

That is why I came here, because I wanted to change careers. I wanted to do something else like counselling, peer counselling, or doing something for people with HIV with all of my experiences. I have been training and doing that with [AIDS service organization].

Participant 22, a gay male who left a career in the private sector, elaborated on the value of life experience within the AIDS service organization he worked for:

One of the things they do here is they do allow life experience to be your experience. They do look for people with education and paper work behind them, and that sort of stuff. But they also give real value to life experience. You have to, I don't think you can do this kind of work without recognizing life experience. I think its life experience that has brought most of us here.

Several participants described how their experience living with HIV informed an ability to better empathize with their clients and others living with the disease. For instance, participant 11, a full time support worker in an AIDS service organization, described how he used his own experience with HIV to connect with and support his clients:

My experience of living with HIV is quite different from my clients because most of them have been street involved and are people living with severe mental health and or addiction issues… So in a lot of cases the only thing we really have in common is the fact that we are both HIV positive… I have been fortunate enough to manage the disease well, whereas their case situation is where their health is deteriorating or they are living with dementia. So there is a certain amount of compassion that I have and empathy based on my own experience.

Participant 22 shared a similar perspective, and described how his experience as an immigrant and a person living with HIV allowed him to develop empathy for his clients, and offer a fresh perspective to his team:

One of my strengths is actually being an immigrant who came also as a refugee claimant… I think all that personal experience helps me to know what people are going through. Sometimes if you are HIV positive, you have not gone through the immigration process,

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and are not going through homelessness, not understanding the system, not understanding the culture, not understanding the language, so it is difficult. I think that's what fills the empathy and that's what one of my strengths are here… I remember a year ago I was the only person working here in my department that was HIV positive. And I think it brought so many perspectives... I think it has been a strength. I think my bosses and the people here know about that.

Participant 19 described facing many past challenges with addiction and homelessness, experiences he was able to draw from in helping others in similar situations:

The fact that I get paid to be me 100%, I feel so damn guilty, everything is out in the open… I actually get paid to be myself. I encourage people just by being who I am, by showing up to work, especially now that people have found out I am [hepatitis-C] positive. They are like, "How the hell did you do this"?

This idea of utilizing life experience as a person living with HIV on the job was not restricted to those working in AIDS service organizations. Two participants described a similar approach to their work outside of AIDS service organizations, both within health and social service organizations. Unfortunately, their experiences were less positive. Participant 6 described conducting street outreach and successfully utilizing his experience as a person living with HIV to connect with youth experiencing similar challenges. Participant 11 also recalled a previous position where he assumed that he would be able to approach his work in a similar manner. Unfortunately he was disappointed at the response within the organization.

I also found there was no mentorship, it being a small organization with 4 staff, and myself… I found there was not a lot of recognition; my experience was different than their experience. I was tired when they were not feeling tired. Maybe I was tired or sick; I don't this it was a good fit.

Additionally, several participants acknowledged specific challenges attributed to their experiences working in AIDS service organizations (above and beyond general vocational

challenges discussed in other sections and chapters). Many of these issues emanated from their

dual role within the agency as both employees and members of an affected community. Two

participants in particular acknowledged a tension in this dual role and described their

determination to meet the expectations of both their co-workers and their peers in the

community. For example, participant 6 reported her determination to be a role model to others.

She asserted, "For me, my biggest challenge is.... I think sometimes I strive too hard to prove a

point that women affected by HIV can do anything." Participant 28, a gay male working full time

in an AIDS service organization for over 5 years described similar feelings, commenting, "I

think when you are HIV positive, I think you feel like you need to come in and try harder and

work harder". Thus, in addition to the sense of satisfaction and reward they took in working

with their peers and contributing to their communities, several participants also acknowledge a

related stress and responsibility connected to this role. Participant 6 had been working in an

AIDS service organization for 2 years. She discussed the pressure and community responsibility

she sometimes felt in her role:

> Those same peers come into your workspace and you're providing
> support to them, they tend to look up to you as if you are past the
> struggles. So, sometimes, you find yourself just putting on this
> persona, like, everything is cool, you know, just to keep them
> going.

This responsibility to others living with HIV was also expressed as a challenge by participant 28,

an AIDS service organization employee for more than 5 years.

> One of the drawbacks I find if you are working for an ASO, not
> that you are a public figure, but you are kind of like a
> representative of the community of HIV… I don't know if it's
> uncomfortable or unwanted, but it's just part of the package. I
> think you maybe might be held to a different standard.

Maintaining privacy and confidentiality while working and serving as a community leader

proved ellusive for some participants. At least one participant reported that being in a dual role

had led to difficulty for him to access health and social services. This was the case for participant

19, a recognized community activist, who described his dilemma accessing needed services:

> Where do you go for support especially in a job like mine, not just
> a regular job? I am a service provider in the AIDS service
> organization field. And you know it is hard to go to workshops
> focused on Hep-C with your participants there…you can't access
> the services in the [community].

Tokenism and issues related to disclosure were also challenges that some participants

attributed to their role as HIV positive employees in AIDS service organizations. Participant 28

explained the importance of being able to retain control over the ability to disclose his HIV status

in the workplace:

> It has kind of been a drawback, sometimes, when other people
> disclose for me. You know? It's like, "Well, you're HIV positive,
> and you don't mind me saying anything," and I am like, "Maybe I
> do today, I was not ready, that was not part of my presentation." So
> in that context I have to have those conversations. I am like,
> "Yeah, well you know, my HIV information is private, it is not a
> secret, right" ... So it really is up to me to share that, and when I
> want to share that, and that changes at different times."

Maintaining privacy, despite being open about her HIV status was also a challenge discussed by

participant 6:

> So, let's say there's a conference happening and, you know, there
> needs to be a PHA attending. Sometimes, I find myself in
> situations where somebody can just come and say, "Oh, they've
> requested some PHA to come and speak. Would you like to go?"
> Even in a setting where it's not a private setting. You know, and
> then I go, "My telling you doesn't give you the right to say it
> whenever you want to say it." So, it's always a challenge to get
> privacy in that context.

Transitioning from the role of service user to that of service provider was a related challenge discussed by one participant. Participant 19, a community activist, described struggling with this shift:

> I have a big challenge from being a service user or client for like 17 years and now all of a sudden - sha-zam - something happens and now you are a service provider. To go from service user to provider is very challenging, and there are not a lot of support systems or infrastructure to help support you.

While many participants were motivated by a sense of commitment to community, various issues and dynamics around engaging meaningfully within the community were reported by some participants. While AIDS service organizations were generally viewed as understanding and supportive environments, at times the dynamics of oppression and discrimination evident in the broader social environment were replicated within these organizations. In this context, accommodating a wide diversity of employees from a variety of backgrounds was reported as an ongoing challenge for AIDS service organizations. While few participants discussed these tensions in detail, community politics related to issues of diversity were identified as obstacles by some. For example, participant 15 reported how issues related to race and ethnicity at times created tensions at work:

> But there's division within the HIV community. You know, gay community, different cultures, like in these immigrant communities, you know. It's not good to eat your own. You know, I don't think we have to. I hate that word tolerance. You know, I think we need to celebrate and, involve ourselves not just, "well I'll put up with you." So I'm trying to change that language, that culture too around my workplace. I work largely with middle class white women… It's still a very white world. I try to change that too, little by little.

Working through issues of race and ethnicity was a priority being addressed within some of the AIDS service organizations in which participants worked. This kind of dialogue was seen as both

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important and challenging. Participant 22, a gay male, described how his organization was

dealing with these issues:

> We have an anti-racism, anti-oppression framework. Twice this
> year we opened up some stuff that created some emotions for a
> couple of our employees. So we ended up coming back and doing
> it a second time, on anti-racism, anti-oppression, on how we are
> feeling. So we spend a lot of education time on learning ourselves,
> learning the people around us, and understanding ourselves and our
> people. I think that with adding the anti-racism anti-oppression bit
> and investing in the people makes the difference in our work place,
> and our ability to serve our participants.

Participant 6, a Black woman, also described the struggles she faced when engaging in these

types of discussions:

> The politics of working there as a PHA is... my personal struggle is
> separating emotion from logic. So, sometimes we're caught up in
> debates, and because I am emotionally invested, you know, I could
> explode and lose the logic side of it. Sometimes that exploding is a
> disclosure in itself, you know.

In addition to issues of race, some participants reported that their organizations were

struggling with the impact of harm reduction philosophy, and accommodating employees who

were using medical marijuana, or not pursuing abstinence as a means of dealing with their

addiction. For example, two study participants acknowledged benefitting from the use of medical

marijuana and obtaining authorization to use the substance during work hours. This was the case

for participant 17 who reported a wide range of employer attitudes and approaches towards

accommodating his legal use of medical marijuana:

> If I was using weed and working at [community agency], I would
> be fired in a minute. But with these in [province], they are more
> lenient if you are using marijuana for your medication. Like, if I
> smoke a joint before I went to work they would not even care. As
> long as it's not like, you know cocaine or anything… I have stuff I
> need to take. I hope it doesn't smell up the whole office. That's my

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> marijuana, sometimes I take it with my pills. If I was working at
> the [community agency], I would not be able to do this. To them
> this would be partying.

Participant 19, a full time employee in an AIDS service organization who also used medical

marijuana, reported actively seeking workplace policies that would address accommodation for

this issue. He explained, "I have to learn things the hard way, but right now we are making

policies and I am wanting appropriate harm reduction in them."

These issues existed in addition to other general challenges that participants noted as part

of their workplace experiences. For some, this included vocational experiences characterized by

financial vulnerability and precarious employment that have been discussed in detail elsewhere.

Nevertheless, it is important to note that of the participants who identified working in an AIDS

service organization, more than half were employed in part-time or contract positions. In some

cases, inadequate resources or lack of stable funding for AIDS service organizations meant that

participants were not receiving competitive salaries or needed benefits. This was the case for

participant 7, who described his situation there as "tenuous":

> I have some benefits but I don't have the full ones, I am on a
> contract. Yeah, and it's to do with funding. There's some core
> funding, but there's some bridge funding also and so it's tenuous at
> times for other programmes that we're trying to run.

Thus, some participants were sacrificing access to good health and medical benefits and financial

stability in order to work in AIDS service organizations and make a valuable contribution to their

communities. The importance of continuing to address these problems and work on issues of

diversity and participation was expressed by participant 6 who commented, "I would really like

us to get to a day where something is done around what it means to meaningfully involve PHAs.

And you know, how can I advocate for myself as an employee in any work setting?" In sum,

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while AIDS service organizations were generally viewed as accommodating and supportive to HIV positive employees, several participants highlighted specific challenges related to their role and the need to continue to address inequities.

7.4.2 Vocational Services

In addition to AIDS service organizations, many participants discussed vocational service provision as a community level structure that influenced their employment trajectories. Drawing on Worthington et al. (2005), The Canadian Working group on HIV and Rehabilitation define rehabilitation services as any that "address or prevent symptoms and impairments, activity limitations, and social participation restrictions experienced by an individual." Furthermore, vocational rehabilitation services are viewed as goal-oriented and client centred processes with the ability to impact a broad range of life domains (Worthington et al., 2005). Unfortunately, several studies have established that access to these specialized services is limited for the majority of people living with HIV in Canada (Worthington, Myers, O'Brien, & Nixon, 2008; Worthington et al., 2005). Nevertheless, although very few are funded to do so, some AIDS service organizations address the employment needs of people living with HIV either through specialized rehabilitation programming or as part of case management services. Frequent strategies within these agencies include vocational information seminars, benefits information, vocational counselling, and career planning (Health Canada & Wellesley Central Hospital, 1998).

For this study, participants were questioned regarding the kind of specialized vocational services they had received as part of their employment experiences and transitions. The majority of study participants (68%) had received some form of vocational services. Nineteen participants (61%) reported receiving services primarily from an HIV specific vocational service provider in

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their jurisdiction. Of these, 16 participants reported receiving one on one support, and three participants reported participating primarily in a vocational support group for people living with HIV. Two participants reported receiving generalized vocational services through mainstream vocational service agencies. Ten participants (32%) indicated that they had received no vocational services whatsoever. All participants, regardless of whether or not they received vocational services described their vocational rehabilitation needs. Participants who had participated in some form of vocational service provision discussed the strengths and limitations of these services. These discussions are summarized within the following properties: social and emotional support, skill development, career planning, benefits counselling, peer support, support groups, creating supportive workplaces, and HIV specific services.

7.4.2.1 Social and Emotional Support

Generally, the ability to access vocational services was highly valued by many study participants. Both participants who received vocational services and those who didn't identified a broad range of needs in regard to vocational rehabilitation. One primary need frequently reported by study participants was for ongoing social and emotional support during and following vocational transitions. Participants discussed requiring support for a broad range of issues including preparing themselves emotionally for work, building their confidence, and managing disclosure. In this respect, a non-judgmental and empathic vocational counselor was identified as an extremely important component of vocational service provision. Some participants reported connecting closely with their vocational counselors while others reported factors that undermined their ability to form a trusting relationship. These experiences underscore the need for counselors with an appropriate skill set and a good understanding of the specific issues experienced by people living with HIV.

Regardless of their background or employment experience, several participants reported requiring ongoing social support from responsive vocational service providers. For example, participant 23, a manager in the private sector, reported needing emotional support for the sense of loss he felt when losing a previous job:

> When I lost my last job, I freaked out, and I had the skill set to get a job, but I needed to have someone to help bring me back to the knowledge that I have. It's like dealing with loss and going through the grieving cycle. I might be different than the other person but I'm still going to go through it.

The need for social support was validated by other participants who had experience accessing HIV specific vocational services. In some cases, participants prioritized the need for ongoing social support above actual assistance in securing a job. This was the case for participant 1, a full time employee in government services:

> I started to go and see them because I wanted to talk about how to interact in a work environment, how to deal with things different. I never, they've never really gotten me a job. I've always kind of got my own jobs. But, I was able to talk to them and interact with them, and there was a support group to help out if I needed it.

Participant 9, a gay male working in health and social services, recalled how gaining support for general life issues was useful as part of the vocational rehabilitation process.

> They were supportive outside of the job search as well. If I was having a bad time for whatever reason, it was okay to bring it, and talk about it, and try and work that through. Also, it gave them more information to work with me with. I found that very supportive and helpful.

This was also the case for participant 6, a single mother who accessed HIV specific employment services:

> One thing that I liked about it was it was not all about work. Sometimes, you know, she would just call and say, "So, how are you doing," or "how the kids are doing"? That kind of also

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reminded me that this is not about me. So, this is another thing that I need to focus on. So, I think that helped.

Feeling comfortable to discuss related personal issues with his vocational counselor was important to participant 31, who was in recovery from an addiction and transitioning back to full time work as a nurse. He discussed needing support to prepare for the emotional challenges he was expecting to face once back at work.

> I think my whole recovery is testament that you can't do it alone…
> the only way I could recover and come back was with support. So
> when meeting with the [vocational counselor] you talk about the
> stresses of daily life, you talk about the challenges of being in
> recovery, you talk about the challenges of dealing with stress, how
> are you going to manage the stress? How are you going to manage
> the shift work? All those kind of challenges, how to get proper
> sleep when doing night shifts? All those kind of things we would
> talk about.

Ongoing social support helped some participants develop the confidence they needed to successfully transition to employment. This was the case for participant 3:

> They gave me the confidence, I guess you can say, to be able to
> pursue active employment... After having been unemployed for
> almost 2 years, or 2 to 3 years it was I think, I lacked confidence in
> interviewing and even presenting myself. They helped me get that
> so that I was able to achieve active employment.

Participant 9 described how the encouragement of his vocational service provider helped him develop the confidence to apply for his current job as a researcher in a health and social services agency:

> Being encouraged to apply for jobs that I didn't think I was worthy
> of applying for, I didn't think I had what they were asking for. For
> the most part that was true, I don't know if it was my history with
> the alcoholism that really got in the way of my employment
> history, but encouraging me to keep going, being supportive
> respectful.

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The uncertainty associated with the episodic nature of the illness undermined many

participants' ability to meet their vocational goals without additional social support. Several

participants discussed struggling emotionally with vocational transitions, in particular, not

feeling prepared or emotionally ready for work. Participant 3 captured these feelings when he

explained, "I didn't want to jump into something that was going to overwhelm me right away. I

wanted to start off small." Patient and respectful support from a vocational service provider

assisted several participants to successfully manage this often stressful and tenuous process.

Participant 9 recalled how his vocational service provider supported him through a period of

uncertainty:

> I took some time off because I realized it was going too fast. I said,
> "I need to take time." I was not ready yet to go to work. Yeah, it
> was early and I just, I was sent home with some paper work to do
> and I was doing it, I was just getting frazzled and emotionally
> twisted. So I thought, "Maybe you are not ready for this." I called
> [vocational counselor] and I said, "I need more time. I am not
> ready," and he was very supportive, he said, "Good for you to
> recognize it, when you are ready give us a call." …. It was a
> difficult call to make, but when he responded I was fine. I was
> okay. I did make the right decision.

Participant 6 appreciated how her vocational service provider helped prepare her for a position in

an AIDS service organization:

> I think one of the biggest things that I liked about that was, I
> wasn't aware what I was walking into… They helped me with that
> perspective in saying, "This is what you are going to walk into. Be
> ready, because this could have an impact on you."

Given the demands of the vocational rehabilitation process, respecting a client's right to self

determination and waiting until they feel prepared was identified as also important to the

vocational rehabilitation process. For instance, participant 4, a recent immigrant and a single

mother, was clear about her career goals, but realized she was not yet ready to pursue them.

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Nevertheless, she had connected with a vocational service provider who felt comfortable waiting

until she was ready to move forward with the process:

> I started to come here because I wanted to have the education to
> get what I need. I am preparing for a new job and I will come back
> and start a job search when I'm feeling more comfortable and
> ready.

Given this need for emotional and social support, the qualities and skills of the vocational

counselor were identified as critical to the vocational rehabilitation process. For participant 23,

the specific training or disciplinary background of the vocational counselor was secondary to

being able to create a strong therapeutic relationship:

> There's got to be a psychological component, it's crucial… and it
> doesn't have to be a psychologist, it could be a counselor, or
> someone with a counselling background… I think that this piece is
> kind of important, just to check in on people. Different people have
> different problems. If you are having a bad day, maybe just being
> able to talk to someone for an hour could help get things back on
> track. Whereas if it's left for a few days sometimes it gets worse
> and it is harder to fix.

Additionally, participant 11, a gay male who worked with HIV specific service providers to find

his current job, described how staff responded without judgment after some initial setbacks:

> Full time employment didn't work out. One of the things I felt was
> I had to go back to them and say, "Guess what, this didn't work."
> And really there was no judgment… They were quite supportive
> in saying, "It just didn't work, don't beat yourself up about it,
> sometimes things just don't work out. Sometimes it is not a good
> fit personality wise who you work with."

The importance of the vocational counselor's role was also highlighted by those participants who

reported negative experiences with vocational service providers. This was the case for participant

24 who felt that her vocational counselor had made unfair assumptions about her:

> One of the first things she said to me is that I should apply for
> welfare … It just struck me as being inappropriate and also made

me think, you know, like. "What are the expectations when I walk in here and see that everybody assumes that this is an off shoot of the welfare office?", which is not the impression I had of the organization before that. So that really set me back a little bit … it made me realize that I don't fit into their main focus group so that made me not want to come back. I didn't like some of the assumptions that I was feeling were being placed on me.

Participant 14, also reported feeling judged by a vocational service provider, an experience that led to him withdrawing from the service:

I find it's impersonal. That's why I've sought other ways on my own… I understand the professional side of things and confidentiality side of things but it did become a little bit intimidating because I felt like I was being judged in the beginning.

Participant 1 also underscored that the effectiveness of vocational services often lies in having the right professional to work with you:

There's another drawback to that, and I'm only trying to be honest here, those [vocational services] will mean nothing if you haven't got the proper personalities there. And I really don't like to say it, but, there's some people that they'll go and they'll leave and it's made no difference. None whatsoever! We've had a couple of people like that.

Given the stigmatizing nature of living with HIV, feeling judged by those tasked with assisting them was enough for some participants to withdraw from service. Frequent staff turnover was also described by several participants as an additional barrier to creating an effective, therapeutic relationship with their vocational service provider. This was particularly true for several participants receiving HIV specific vocational services. For instance, participant 9 described how being transferred between multiple workers hampered progress on his vocational goals:

When I first came in I spoke with [vocational service provider]. Then I was working with [vocational service provider] because he

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got promoted… Then they transferred me to another worker. Things were not progressing. Then I was with [vocational service provider] who is no longer here, she is up the road now. She had to go for surgery.

Participant 3 described being satisfied with his progress despite a similar experience:

When I first started with the [vocational program] I was seeing one person and then she got a job elsewhere within [the agency], I believe it was. So I was transferred to another job developer and then she was leaving to another position so then I was transferred to another job developer. I was kind of bounced around between three different people, I was kind of juggled there. But nonetheless I received the support that I needed by the time I was transferred to the second person I had already had the interview with the school bus company and I already had the job so I didn't need much more support after that.

This was not the case for participant 19 who felt that staff changes were not well communicated; an experience that undermined his confidence in the service. He recalled, "Well, they did not even explain properly that they were moving on, next time I ran in to them they were in a different position with [the agency]. All of a sudden I got someone else new."

Several participants reported feeling confident that their vocational service provider would understand their anxiety regarding disclosure of HIV and take measures to protect their privacy. For some, this was a reason they sought out HIV specific vocational service providers. Participant 15, a recent immigrant, described the importance of ensuring that his participation with an HIV specific service provider did not come to the attention of his employer. He explained, "Talking about HIV... usually the company they want to search, the company they don't know [vocational service provider] is helping me because I do not disclose somebody is helping me." Additionally, participant 3 highlighted how his vocational service provider assisted him in preventing disclosure and managing his anxiety:

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> What is beneficial about it is the fact that there is some understanding as to the hurdles that I'm dealing with; you know not disclosing my status. When I first got hired, there was a medical report that needed to be filled… I brought the form into my job developer at the time and I discussed it with her and she said, "It says nothing about your HIV status, don't even worry about it. You know what, this is nothing. It should create no problem." Sure enough it did clear… They were very helpful in helping me to address these hurdles without necessarily disclosing my HIV status.

Thus, the need for ongoing social support as part of the vocational rehabilitation process was identified by many participants as being important. This was frequently the case both for issues directly related to employment and other life issues that act as barriers to successful vocational transitions. Specifically study participants reported using these supports in preparing themselves emotionally for work, building their confidence and managing disclosure.

7.4.2.2 Skill Development

In addition to social support, participants described skill development and support for job search as a key component of vocational service provision. Three specific areas mentioned by participants included preparing for interviews, developing a resume and planning for a career.

Participants who had participated in vocational service provision reported interview preparation as a job search skill that they benefited from. For example, participant 3, a gay male with little job experience, acknowledged that vocational service providers were able to help him perform his best in a job interview:

> What I found most helpful was we set up an appointment, and they gave me a mock interview. I came in, and they were an employer, and I was applying for a job. After all was said and done, we sat down, and went over it, and what I could do better, and what I lacked, and what I did great, and that was very helpful.

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Participant 20, a recent immigrant with little experience in the Canadian job market, described

how working on his interview skills assisted him in securing full time employment in his field:

> When I first came here, I had some interviews, but I felt that
> something did not work properly at the interview. I missed a few
> things presenting myself a bit of a wrong way. One of the major
> problems or issues was the lack of experience to convince the
> employer that I am the right person for him.

Developing their interviewing skills was seen as a valuable opportunity to a broad range of

participants including those who had not accessed vocational services to date. Participant 5, a full

time financial services employee, described how keeping these skills up to date was sometimes a

challenge:

> The actual interview because it changes so much, and you can't
> just talk about your personal life when you go for an interview. It's
> all job-related so when they say, "Tell me about yourself," this is
> where you sell yourself for your job, for what you're qualified for,
> based on why you're sitting in that room and you're saying, "I'm
> qualified for this position because I have this, this, and this." If I
> had to do it right now I'd have to refresh all over again and so I
> probably would utilize [vocational services provider].

In addition to developing their interview skills, study participants highlighted the importance of

developing an effective resume; a skill set that several had developed with support from

vocational service providers. Participant 14 described how working with an HIV specific

vocational service provider assisted him in developing an effective resume:

> Their resume help - amazing, phenomenal. I didn't realize your
> resumes are now like a portfolio. Because when I did resumes,
> they were just basic. They're fantastic with people, to pull that
> together, and they had a lot of resources to pull from.

Several participants attributed support in developing their resumes to successfully securing

employment. Participant 20, a professional working in the business sector, recalled how working

with an HIV specific vocational service provider to improve his resume led to being hired for his

current position:

> After several changes to my resume, really minor changes at the
> end, all of a sudden I started to get phone calls, things happened.
> So some people could say it was after the recession so the market
> was a bit better, improvements of positions, and more options in
> the market. Still when I take the old resume with the cover letter
> before and after [vocational counselors] assistance, there was a
> major change… it was not the same definitely not.

Participant 21, a gay male working full time in an AIDS service organization, described a similar

experience. Also an immigrant, he discussed the importance of understanding the job market in

Canada and tailoring his resume in order to succeed:

> I didn't know how to build a resume, like a North American or
> Canadian resume and all that; the rules of the game, and
> understanding the labor market. So I had someone who helped me
> with everything, and I really appreciate that. That was the time also
> I wanted to be self efficient. So at some point, when I got what I
> needed, I was able to fly solo.

Vocational service providers were also effective in supporting study participants to develop their

skills in a variety of other areas. A few participants described benefiting from computer skills

training offered by vocational service providers; opportunities that participant 11 and 12

attributed to keeping their "skills current' and in helping them "prepare for a job". Others

reported receiving financial assistance to attain first aid certification and other job skills training

programs.

Beyond the basics of vocational skill development, participants described a need for

career planning and career development services. Expanding upon the requirement for ongoing

social support, several participants described a need for assistance in preparing for and managing

career transitions, remaining competitive in the Canadian labour force, and in fully realizing their

vocational goals. As participant 19 explained, "Teaching people what to do when they get a job."

For example, a few participants had a clear sense of their career goals but lacked the confidence

and the knowledge to effectively achieve them. Participant 3, working part time in the

transportation sector, described his ambition to transition to full time employment and his related

sense of caution and insecurity:

> I'd like to do this employment for a period of time to gain the
> experience in the driving field so that I can transition into maybe
> the [employer] whereas then there are great benefits package and I
> could retire with the pension. But then again that's full-time and I
> don't know if I'm quite ready yet to transition into something full-
> time and then I don't have much experience either I mean I've
> applied to them in the past and they never called me.

This sense of uncertainty and insecurity was shared by participant 12, a hospitality services

employee, who described seeking support while preparing for his next career transition:

> That is a question… I don't know yet really to be honest I am still
> totally insecure, 100% insecure, because I have been doing the
> same thing for so many years... Back home I worked at a job
> agency, then the hotel at the front desk, catering. I have been
> working with customers, but I don't know about an office. It is so
> different, it is two different worlds. That is why I am so insecure
> now. I need to see the career person.

Contributing to this sense of insecurity was the competitive nature of the Canadian labour

market. Despite their current vocational success, several participants acknowledged requiring

additional support to remain competitive in the current environment. Participant 7, a straight

male in his 50's, described the pressure he felt in the current labour market, remarking, "They're

really competitive about this. This isn't the seventies, when I left school, when you had your pick

of jobs. You know, it's a very competitive workforce. You have to sell yourself and you have to

educate yourself." Participant 15, a general labourer expressed similar thoughts:

> So I find it very hard to find a job, it is very, very hard... You have
> to go out and fight with people who have much better conditions,
> because they have the better condition of health. In my case now I
> have the age, now I am getting old, plus I have the HIV. So I have
> some disadvantages really to compete in the free market…

The rapidly evolving nature of the workplace was also a factor, identified by participant 11, who

highlighted the need to continually maintain and upgrade vocational skills:

> I don't know what a lot of people have reported, but I know that
> from the time I got my position working in advertising to when I
> was laid off, it seems like the whole world has changed, from
> paper to electronic … I don't remember doing a cover letter before.
> It seems like the whole labor force, and looking for work has
> changed.

Remaining competitive was a particular issue for newcomers to Canada who described

the added burden of acculturating to the Canadian labour market. Participant 21, an immigrant

from Latin America, described needing support to conduct a job search in a new cultural context:

> I didn't know that after an interview you have to send a thank you
> note, or how to act in an interview here in Canada. The standards
> are completely different from Latin America to Canada… I
> remember my employment counselor at the time, she said,
> "Definitely you are ready, and you need some small things that are
> going to be helpful." Basically those things were Canadian culture
> competency and networking skills.

This was also the case for Participant 20, who had immigrated to Canada from the Middle East:

> Just to gain the Canadian experience. It was a major part of it and I
> know that this time I felt kind of desperate; I felt that I was out of
> the market for about 9 months, and I was looking and looking and
> looking. I tried almost everything, so I'll have my first foot in the
> market, I will go volunteer, I will find a way to be a mentor,
> something like that, just to get in to the market.

Participant 15, also an immigrant from Latin America discussed the challenges he faced having

his credentials recognized in Canada, a process that his vocational service provider was well

equipped to assist with:

So I had to contact my university in my country, they send my
documents, and my marks. After that they come out with a letter
saying that my degree that I had in Columbia is equivalent to a
bachelor degree of 4 years in Canada. So they [vocational service
provider] pay for that, so they help me with that, it is a very
important program.

Consequently, support for career development was important as study participants

endeavoured to remain competitive in a challenging job market. This involved supporting

participants in achieving their career objectives as opposed to just finding them any job.

Participant 17, an employee in an AIDS service organization, advised the importance of

engaging participants in exploring their vocational goals:

Take a look at their goals their values. I think that's the most
important first step to put the person into context and have them
understand more about themselves, like work practices relationship
styles, and to get them a really good sense of that so when they
move forward they are more likely to be successful in the job.

This was a task that some vocational service providers reportedly took to heart. For instance,

participant 6 described how her vocational service provider stayed in touch with her after she

secured employment and encouraged her to continue to apply for opportunities. This

encouragement was essential in helping her develop a career as opposed to just being stuck in a

job:

I think they also made me realize my potential because.... I actually
remember on countless times as I was employed, they would
constantly send me job postings and say, "You know, you would
be really good at this." And, "I thought you would be interested in
this." So I knew I wasn't meant to be stuck there, you know, and
that's how I got the job that I have now.

Others described the support they received while managing a career transition and their intention

to continue to work with their vocational service provider until they felt comfortable with their

achievements. For instance participant 11 described how, despite currently being employed, he was planning to work with his vocational service provider to explore educational opportunities:

> The next part will be … to go back to school and hopefully they will also be able to help me, not so much choose the program, I am pretty sure of where I am going to be going, but helping me find funding and I hope that, and I know that is part of their mandate is helping in training for future employment.

7.4.2.3 Benefits Counselling

As discussed in earlier sections, many study participants reported struggling to understand and negotiate a variety of income support policies and programs. Whether deriving income from provincial disability income supports, private long term disability benefits, Canada Pension Plan, or other combinations of income supports; many participants reported being confused by the complex details and lack of integration commonly associated with these programs. In many cases, these factors served as vocational barriers to participants engaged in vocational transitions. Some participants were reluctant to jeopardize access to established income supports and health coverage by changing their employment status. For some, the prospect of transitioning to full time work or accepting a new position meant risking their current income and established benefits (however imperfect they were). Gaining a full understanding of the impact that a change in employment would have on their access to essential benefits was identified as a priority for many study participants. Participant 17 recalled, "I must have had questions around leaving my full-time job, and going back to school, and how does this affect my own ODSP." Participant 6 also described this common dilemma:

> You really have to know, if you're going to full time employment, how it's going to affect your drugs, your benefits, and also take a look at your work benefits. It's a lot of homework. It's a lot of homework. You have to know your deductibles. I think that's also

a gap that most PHA's have, which is why some people just
decide, why the headache? I am going to stay on ODSP.

The difficulty of managing these details and ensuring that coverage will be in place was

described by participant 12:

> If I find a job, I have to pay a year for Trillium… it is all the stuff I
> have to think about, I did not think about that before I started with
> [vocational service provider]… For example the rent, and dealing
> with medication, trillium, all this stuff. I am willing to do it. It is
> complicated at the same time it is like going back to my original
> life like I had before, it is not really easy.

Subsequently, benefits counselling that addressed issues with public and private benefits

providers was seen as a valuable component to vocational services provision. Several

participants who had worked with HIV specific vocational service providers described the value

of working with someone who has knowledge and expertise related to income support and

maintenance. Participant 6 expressed the importance of benefits counselling. She explained,

"You'd have somebody, you'd bring your work benefits to a counselor, and then see how you

need to play it out. Because, once you disclose this plan ODSP shuts down." Additionally,

participant 20 reported how benefits counselling, provided by his vocational service provider,

helped deal with the uncertainty he felt when transitioning from public income supports to full

time work:

> I think the only issue that I had was about the benefits: when I can
> be supported by ODSP, what the impact will be on my drug plan,
> and other things. That was quite a big issue. I still find it kind of
> tricky, especially when you are coming from a different
> environment and culture.

This was also the case for participant 3:

> The support that I really needed was just transitioning from
> unemployment into, "Okay now I'm working what I need to do in
> terms of my disability and making sure that I report everything

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> correctly."… Because they give me an additional benefit of $100
> for transportation, or clothes, or whatever else that I need. The
> person that I was transferred to after helped me in terms of that
> aspect.

According to some participants, public benefits providers were not always forthcoming when sharing the full range of benefits they were eligible for, leading to a degree of confusion about supplemental benefits. Working with a third party who was knowledgeable about income support programs was an extremely valuable experience. This was the case for participant 6, a single mother, whose vocational service provider helped her gain access to subsidized daycare and subsequently helped remove a barrier to work:

> They also helped me, because I wasn't aware of what I could get.
> There was a time when I spent about four months paying for
> daycare. We're looking at almost $400 for two weeks. Yes. So,
> they helped me get that too, get my subsidy, and, they helped me
> get back onto ODSP. So, that, that really helped.

Unfortunately, assistance or information on dealing with private long term disability providers was reportedly less accessible. Participant 14 recalled needing support when dealing with his long term disability provider, but finding little available:

> Maybe a little bit more knowledge on the long term disability… I
> wasn't provided with that kind of network. But that would've been
> extremely helpful at the time because then I would have known
> what steps were going to happen or what to expect.

Thus those participants who received vocational services as part of their employment trajectories reported benefiting from benefits counselling and vocational service providers who were knowledgeable about income support policies and programs. Several participants articulated the need to have benefits counselling closely integrated into vocational service provision as many needed support in identifying the consequences and opportunities available from both private and public benefits providers.

7.4.2.4 Peer Support and Mentorship

Peer support and mentorship was a vocational service need often discussed by study participants. Unfortunately, it was not currently provided by any vocational service providers, and very few participants reported receiving such a service. In particular, the need for peer support and mentorship was identified by several of the women participating in the study. For example, participant 4, a recent immigrant from Africa, described how she felt when she saw other women who were living with HIV and succeeding at work:

> Yes, a program for people who are working and who have AIDS is really important because… when you see someone like you, you say, "Well they could do something like that, why not me"? When I look around I see that those who have a really good position and have money; they are not coming here anymore. It's something they've already figured out, and they can use their experience to push those who are behind to move up.

The importance of working and learning from her peers was also reported by participant 24, a married mother of teenagers. She articulated the skepticism she felt when dealing with vocational service providers who did not include HIV positive peers as part of their service model:

> The one thing I don't feel totally comfortable about this place is that I think there are a lot of people here who aren't HIV-positive, and I just think, "What do you know?" I don't know for sure that people aren't, but sometimes I just thought, "I bet you're not positive." when talking with some people. I don't have that same feeling at [service provider]. I don't know if it's just the mentality there, or if they're all positive. I don't know, it is really important to know. I went to a workshop that a [community] group put on, it ended up just being a really small group of people, all of whom I knew. There was mostly women at this group, and the women who came in to lead it started out by saying that she was positive and had been for more than 20 years, and that made me take her more seriously frankly. I really appreciated that, because she could also then personally you know when sharing experiences with health

issues she could incorporate her own experience and that to me was really important.

Participant 5, a single mother, regretted that peer supports and mentorship wasn't more available as part of vocational service provision:

> Only through [another service provider] did I get some peer mentorship. I would go away on retreats, and there would be workshops over the course of the day where you could learn different things. That would be a good thing to consider for the future; mentorship for those already in the workforce, almost like an AA type of concept, "this is who I was, this is what I did, and this is where I've come to."

Others in the study sample also supported the idea of peer supports and mentorship as part of vocational service provision. For instance participant 12, a gay male, discussed receiving mentorship from another person living with HIV; a service that was provided by another agency. Nevertheless he found it an affirming experience, and felt it would be a valuable addition to vocational service provision:

> He gave me a lot of information... At one point he was mentoring me when I had a problem with medication, with my memory, concentration, that stuff. He was really good.

Participant 29, a gay male working in an AIDS service organization received support from a mentor in the workplace. He described the benefit of this informal workplace mentoring arrangement:

> There was an organization that came here to help people get back to work. Last year for a while I did talk to that lady and I think [mentor] brought that program here. What I have found was you know [mentor]was just someone I used, a door was open, I could come to, I could ask him questions, I could get help with my resume or cover letter... He was always encouraging, and it was like this one somebody who believed that I could do things. It's good to have other people have confidence in you, and see things in you that you may not see. I think that's a very good thing if people can find a mentor.

Unlike other participants, for participant 1, the notion of peer didn't exclusively mean that the other individual needed to be HIV positive. He articulated the value of having a peer relationship with others in the workplace:

> To be treated as a peer, one-on-one I think would be superb. I think it really works, and I think it has a better affect than groups, because it's more concentrated… They can be there just to listen to you, or they can be there if you want some advice. One on one, I think, would be superb. I think it has to be a proper match, and I'm not talking about both being HIV.

In sum, many participants mentioned having been involved or wanting to be involved in peer support or mentoring relationships; unique services they found to be extremely valuable. Some participants also discussed the lack of availability of these programs within other AIDS service organizations and certain programs being cut; establishing peer support and mentorship as a vocational service gap.

Another such gap was the availability of vocational support groups. Vocational groups provided some participants with the opportunity to connect with their peers in a safe environment. Participant 19 discussed the need for more emphasis on delivering vocational services in a peer group format:

> They need to get in to group counselling, group sessions, it does not have to be one on one…. some of the knowledge does not have to be transferred one on one, it could be in a group setting because a lot of it is basic.

Unfortunately, vocational support groups were not readily available as part of vocational service provision. Nevertheless, two participants recalled participating in a group organized to support people living with HIV through vocational transitions. They both described the value of this approach. Participant 26 described the inspiration he felt from having participated in a peer support group organized to discussed vocational issues:

I just saw other people work, you know. If I saw people miserable and unhappy, I guess I would think twice about it and maybe go on disability. If anything, I kind of looked at people living the fullest and the best. There were a few of them who said, they are living 30 years, and they are still productive, they are working... I just looked at them as role models. They were talking about health care and taking a medication on time. I looked at them as role models in many ways. There was this one guy in particular he was in his 60's … I could never be as good as he is but he was a bit of a role model for me. He worked, he was active, he had it for 30 years and he just looked great. There were a few people that really inspired me in those groups.

Additionally, participant 29 discussed how a specific vocational support group allowed him a safe space to work through the decision making process and time to explore his vocational options in a low pressure environment.

It was nice also to have [service provider's] group, which was good. I think the good thing about it was there was no pressure on me, like maybe with a government agency… There was no pressure; it was me in control of the whole thing. It was nice when the timing was right, when that job came up in the agency. I was ready, and I think I had help. I didn't go to a support group looking for work, the kind of group that [service provider] had allowed me to think about it … at that time I still didn't know, I was still thinking who knows what could happen.

7.4.2.5 Creating Positive Workplaces

As discussed earlier, finding and securing work in a supportive environment was a priority for many participants and one reason that the majority chose to work with HIV specific service providers. Subsequently, many participants felt that these vocational service providers had an important role to play in helping to create positive workplaces for people living with HIV. Strategies discussed included outreach with employers and advocacy.

Participant 4, an immigrant and single mother was reportedly terrified that her employer would find out her HIV status. Explaining that, "The real problem is discrimination," she emphasized the importance for vocational service providers to reach out and sensitize employers:

> People don't have information about AIDS. They are not educated really. They should let people understand without shame what it's like. We have to educate people more and more… They should do more education with employers and educators to make things easier for those in the work place.

Participant 2 agreed and described the benefits that he felt would accrue from specific strategies aimed at better educating employers:

> To feel that you can be who you are, have what you have, and still be in that environment. It would be nice to know that, in work environments there are people that you can discuss this with. To just feel that it's not taboo anymore, that it's a day to day thing, and that people can feel more comfortable being who they are.

Several participants acknowledged that their vocational service providers did conduct outreach with employers and reported feeling relieved. In several cases, they trusted that the employers they were being referred to would not discriminate due to HIV status and would not be homophobic. For example participant 8, a gay male working in the financial services sector expressed trust that his vocational service provider had appropriately screened employers:

> I feel it has helped me a lot, because they are not going to send me to a homophobic company that don't want me because I am HIV positive. This program gave me a lot of strength to go forward.

Participant 12, also a gay male, expressed similar thoughts, explaining, "Part of that is knowing that they are going to be prepared, and you are not going to a homophobic employer or someone who is going to discriminate against HIV."

In addition to outreach and education, some participants felt that vocational service providers should be actively advocating on their behalf. A range of strategies in this area

included advocating at the individual level and at a broader policy level. For instance, participant

19 felt that HIV specific vocational service providers should generally be engaged in,

"advocating more for the individual and for individual rights." Participant 4, a newcomer from

Africa suggested that her vocational service provider could be better prepared to assist her in

managing unfriendly systems and institutions:

> Sometimes I think they should try to meet with people who are
> responsible for the [organization], because when I met with her she
> called the boss that hires workers and she didn't get her. And I told
> her that is one of the problems I have. Spending some time with
> those people, maybe have a meeting, or a chance to discuss with
> people … try to have more information, to know how they're doing
> because when I said I wanted to do something like that she didn't
> have anybody that she could ask to see how is it working, how are
> they dealing with that. They don't have any information about that.

Additionally, participant 6 felt it would be helpful if HIV specific vocational service providers

were more confrontational when addressing employers and advocacy issues:

> I would love to see them be more aggressive and more demanding.
> …sometimes I ask myself whether they even realize the power that
> they can have. You know what I mean? Are they holding
> employers accountable? Cause I think that's another piece that's
> important. Of course, I'm not saying they should go out telling
> people what to do, but there should be some accountability of some
> sort…   also, I would also like to see them going into consultation
> with employers. Whatever, to say, you know, "How are you
> working with PHA's"? You know. "Would you work with a
> PHA? And if so, what would you put in place"? And advocate.

Thus several participants recognized the need for their vocational service providers to work

beyond just an individual approach and engage in outreach and education with employers as well

as conducting advocacy on pressing issues affecting people living with HIV.

During the study interviews, many participants discussed the benefits and disadvantages of receiving vocational services from an HIV specific service provider versus mainstream vocational agencies. The majority of participants who addressed the issue indicated a preference for HIV specific vocational services. In sum, ten study participants reported feeling most comfortable receiving vocational services from an HIV specific service provider versus three who indicated a preference for mainstream supports or said that it didn't matter either way.

The stigma and discrimination that continues to surround the disease was cited as a motivator in seeking services from an HIV specific vocational service provider. When asked if receiving services from an HIV specific agency was important, participant 17, a gay male, responded:

> Yes, it was important to me, and yes I do think it's important to create a safe space for HIV-positive people. Because there is so much stigma and discrimination and if a positive person doesn't feel safe enough to disclose to their employment counselor then they're not going to be as effective as they could be.

Participant 2 received services from an HIV specific vocational service provider and reported appreciating that he could disclose his illness without fear of stigma or judgment:

> You get to be yourself, you get to explain yourself, you get to be honest. It's great that there are things there that will help people living with this disease because sometimes people are scared to talk about it. People are not that educated, and it might be hard to kind of disclose certain things, and you might hold back. So it's nice to go to a place where they know who you are and what you have, to help you.

Participant 29 participated in a vocational support group that was delivered by an HIV specific service provider. He described the sense of safety he felt in this environment:

> Yes also the comfort of all these other people are HIV positive and they are in the same situation of not knowing anything. Like not knowing how long they are going to be around, not knowing what the future holds, and we all have the same condition. There is something comfortable about that rather than if I am going in a group where it is just people off the street that might be looking for a job. I think it is, kind of like, with an HIV positive person you have a bit of extra baggage you are carrying.

A few participants chose HIV specific vocational service providers for their specific knowledge and expertise in working with people living with HIV. Participant 9 reported choosing an HIV specific vocational service provider as he felt that they would have more specific information about the issues he was facing:

> I think what attracted me to here was the fact that they were an [AIDS service organization] and they would have more information about HIV and job searching. At that time I did not really have that much knowledge about it, especially after being unemployed technically for as long as I had been. That was a big gap.

Participant 4, a recent immigrant from Africa had not received HIV specific vocational services in the past. Nevertheless, she indicated a preference to work with an HIV specific service provider should she need to going forward

> I would actually prefer HIV specific support now to help me engage in future employment, if necessary, because everybody else would be of the same stature as myself. So they will know the kinds of questions that are going to be asked and have some idea about who's hiring and who is not and it would be not-for-profit versus the private world where I am right now and so I would integrate that assistance for sure int 5 black female

Additionally, participant 11, a straight male and an immigrant from Latin America, acknowledged an openness to working with mainstream vocational service providers but also feeling that an AIDS service organization might have some specialized knowledge that would be useful:

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> When I came to it, I think I could have worked outside of an
> [AIDS service organization]. But when I came to it, I thought you
> know they might have information I don't have about being HIV
> positive and job searching.

Several participants reported a preference for HIV specific vocational service providers who are closely integrated (physically and philosophically) with established AIDS service organizations and other community structures. For instance, participant 11 had been referred to and worked with mainstream vocational service providers in the past. He eventually returned to an HIV specific vocational service provider due to its integration within his community and with his volunteer position:

> No, when I first came on they recommended going to visit a couple
> of other organizations to see what they have. In [province] you
> have to choose a service provider and once you have chosen you
> stick with them. So I did go to see [vocational service provider] at
> one point. I was going to see the [social service agency] as well. I
> didn't eventually go with them … Both because it was local to
> where I am living, it is local to where I am volunteering, it seemed
> a natural fit just to stay with [HIV specific vocational service
> provider].

Participant 21, a gay male who had recently immigrated from Latin America, appreciated that his HIV specific vocational service provider was well established in the HIV community, providing him with the opportunity to receive a variety of services within one community agency:

> I was in that stage of understanding my HIV. Here it is a one stop
> shop. You come here and you can do everything, instead of going
> here and there. I was going through a difficult time so I didn't want
> to get to know more people and other organizations, deal with
> those organizations, and transportation. So everything was close, I
> have been living and working here since I moved to Canada,
> everything is pretty convenient.

This was not the case however for all participants. A few participants articulated a clear

preference for mainstream vocational service providers. For most, this preference arose from a

fear of being further labeled as a person living with HIV. Participant 1 explained this reasoning:

> To me it adds to the stigma. It's like being labelled. You have
> [service providers] come in. Well, are they specially trained in
> HIV? Well, do I really need that, for Christ's sake? They know
> I've got it. I'm here. I don't even think they should know.

Participant 23, a gay male, also felt that he would be better served by a mainstream service

provider since it meant he wouldn't be labeled as someone living with HIV:

> I personally would find it difficult to come, because I feel like I am
> being labeled as someone with AIDS, and whether that's right or
> not I don't know. I personally would prefer to go somewhere where
> other people went. Just because I've got HIV doesn't mean I need a
> special counselor… I would find it really difficult to come here
> and do a job search because I'm being labeled as someone with
> HIV. I am just someone who needs a job, or help getting a job, that
> might be slightly different than someone else… I don't want an
> AIDS vocational rehabilitation counselor if that makes sense.

Participant 3, a gay male working part time in the transportation industry, had no preference. He

explained, "I don't think it would necessarily matter to me, what is beneficial is the fact that there

is some understanding as to the hurdles that I'm dealing with."

Thus not all, but most, participants indicated a preference for HIV specific vocational

service providers versus those in mainstream agencies. Several reasons were cited including the

specialized knowledge offered by HIV specific service providers and their integration within

other community structures. Participants reporting a preference for mainstream vocational

service provider most often did so out of a fear of being labeled.

7.5 Chapter Summary

This chapter identified findings related to the fourth and fifth major categories in this framework; the institutional and community structures that influenced participants labour force experiences and were connected to the overall process of working successfully. The category of work included a variety of institutional factors that shaped workplace environments and influenced participants' experience in the workplace. Additionally community factors such as AIDS service organizations and vocational services were identified as having a potential mediating effect. Chapter eight will continue this discussion of environmental influences by focusing on the seventh category, public policy.

CHAPTER EIGHT: PUBLIC POLICY

8.1 Introduction

As indicated in Chapter Seven, three key environmental structures shape and influence participants' successful experiences in the labour force. The fourth category was work and factors related to the key institutional factors that participants described as contributing to positive workplace environments. The fifth category was community factors; those primarily related to mediating structures in the community that could support participants' success in the labour force. Both of these categories were described in chapter seven. This chapter will discuss the third environmental structure, public policy; the sixth and final major category in this framework. Public policy relates to the national and provincial laws and policies that shape and impact labour force participation for people living with HIV. Within this key category are descriptions of subcategories including income support policies, access to treatment, housing policy, and stigma and discrimination in the policy domain. This chapter describes the properties and dimensions of these two important categories in detail.

8.2 Public Policy

In his original treatise outlining the ecological perspective, The Ecology of Human Development, Urie Bronfenbrenner (1979) described public policy as an important macro system factor "that is most critical for the cognitive, emotional and social development of the person." (p. 8). In contemporary ecological models, public policy refers to settings within the broader social system which construct and enforce policy or legislation including health, legal, educational, and governmental institutions (McLeroy et al., 1988). It is in the public policy domain where the social and economic factors that structure individual employment trajectories

are constructed and challenged. When approaching these systems it is essential that the reciprocity implied in ecological models is not overlooked and that public policy is understood as within influence (Sallis et al., 2008). Thus factors in the public policy domain that impact HIV and employment include national and provincial laws and policies as well as policy advocacy and citizen involvement.

8.2.1 Income Support Policies

Similar to many others living with HIV in Canada, a majority of study participants reported relying on federal and provincial public income support policies and programs to provide them with a sustainable income at some point in their lives. Perhaps the single most important public policy provision available to people living with HIV, the programs commonly supporting these individuals include the Canada Pension Plan Disability Program, Employment Insurance Sickness Benefits, and provincial social assistance benefits (Canadian HIV/AIDS Legal Network, 2005). Due to increasingly flexible employment provisions structured within Canadian public income support policies, a broad range of engagement with these programs was reported. Many participants recalled a history of receiving full benefits, several combined part time or casual employment with partial income support benefits, and a few maintained full time positions while receiving transitional health benefits. Consequently, participants' experiences with public income support policies and programs played a major role in their ability to work successfully and income supports were described as both facilitators and barriers to successfully working.

8.2.1.1 A Summary of Provincial and Federal Income Supports

Prior to discussing participant's experiences with income supports, it should prove useful to briefly summarize these programs. Although all study participants were employed, the

majority reported relying on provincial social assistance programs at one point. Income support

programs reported by participants included the Ontario Disability Support Program (ODSP),

Employment and Income Assistance (EIA) in British Columbia, and Assured Income for the

Severely Handicapped (AISH) in Alberta. Additionally, one participant reported receiving

benefits through the Canada Pension Plan Disability (CPPD) program. A summary of these

programs, available benefits, and their employment related provisions is found in Table 8.1.

In general, these programs provided recipients with extremely limited incomes that were

well below the poverty line and Statistics Canada's low income cutoff (Statistics Canada, 2012).

For instance, in Ontario, ODSP recipients receive just $1075.00 monthly (Government of

Ontario, 2013). In Alberta, the base benefit rate for AISH recipients is $1577.00, and in British

Columbia it is $906.00 (Government of Alberta, 2013; Government of British Columbia, 2013).

CPPD recipients may receive a maximum monthly benefit of $1212.90, although the average

benefit tends to be much lower (Government of Canada, 2013). In addition to basic benefits,

provincial income supports provided health care coverage, including prescription, dental and

vision coverage as well as a range of means tested supplements such as special diet benefits and

transportation benefits (Stapleton & Tweddle, 2008).

Many provincial and federal income support programs included flexible policies that

allow recipients to engage in paid employment. This was the case in the provincial jurisdictions

that served as the focus for this study. The CPPD, ODSP, EIA, and AISH all featured a variety of

provisions that encourage recipients to consider working. These provisions included earnings

exemptions, transitional health benefits, automatic reinstatement, and employment supports.

These provisions were described by many study participants as assisting them to work

successfully.

Generally, to be eligible for provincial and federal income supports, recipients must not possess assets above a specified maximum, and must be unemployed (Stapleton & Tweddle, 2008). Earnings exemptions are policies that allow recipients to earn employment income while retaining a portion of their income support benefits. The approach to earnings exemptions varied slightly within each provincial and federal program. However, typically recipients were provided with a set amount of employment income which they could earn without penalty, after which the remaining income was clawed back. The province of Ontario had the most generous earnings exemption policy allowing ODSP recipients to retain 50% of their income from employment (Government of Ontario, 2013). In Alberta AISH recipients were allowed to retain $800.00 of net employment income monthly plus 50% of the balance (Government of Alberta, 2013). In British Columbia, EIA recipients could earn up to $9600 yearly with no monthly maximum (Government of British Columbia, 2013). Those receiving CPPD were allowed an annual earnings exemption of $4,400.00 with no penalty.

In addition to earnings exemptions, transitional health benefits were important measures that allowed study participants to work successfully. In Ontario, ODSP recipients were allowed to retain access to their Ontario Drug Benefit Plan following a full return to work. Thus, in situations where the employer does not offer benefits, recipients could continue to receive full prescription coverage, vision care, and dental care (Stapleton & Tweddle, 2008). This was also the case for the other two provincial income support programs that participants reported accessing. Within CPPD there were no provisions for health benefits of any kind.

Additionally, automatic reinstatement policies were also seen to facilitate employment. These policies allowed income support recipients to return to full benefits after working for a

period of time. In Ontario, ODSP recipients were eligible for a rapid reinstatement to benefits if

unemployed in the future. CPPD allowed for automatic reinstatement up to two years from the

Table 8.1 Income Support Policies Accessed by Study Participants

Ontario Disability Support Program (ODSP)	
Administering Department	Ministry of Community and Social Services
Income Provisions	Earnings exemptions – 50% of net employment income $300.00 deduction for disability related employment expenses
Drug Benefits	Ontario Drug Benefit Plan (100% of prescriptions) Vision care Dental care Ambulance
Transitional Health Benefits	Ongoing health related benefits to recipients who leave ODSP for employment until they receive employer health coverage
Employment Supports	Employment consultation and planning Employment preparation and training Job placement services Job coaching, tools and equipment to commence employment Mobility devices
Reinstatement Provisions	Eligible for rapid reinstatement
Benefit Rates (single person)	$1075.00 monthly (2013) (support +shelter allowance) $100.00 month work related benefit $500.00 employment transition benefit
Provisions for HIV Medication	ODSP claimants receive coverage for HIV medication via the Ontario Drug Benefit Plan Clients leaving ODSP for employment receive coverage until they receive employer health coverage The Trillium Drug Plan is available for those who do not receive health care coverage through employment or ODSP

Alberta– Assured Income for the Severely Handicapped (AISH)	
Administering Department	Alberta Seniors and Community Supports
Income Provisions	Earnings exemption - $800 of net employment income plus 50% of the balance
Drug Benefits	Alberta Health Plan Insurance

	Prescription drugs Vision Care Dental Care Ambulance
Transitional Health Benefits	Clients leaving AISH for employment receive coverage under the Alberta Adult Health Benefit Plan
Employment Supports	General employment supports (unspecified)
Reinstatement Provisions	No reference to this found in the policy
Benefit Rates (single person)	$1577 monthly (2013) $36.00 monthly for special diet
Provisions for HIV Medication	HIV medication is provided free of charge via an outpatient clinic to all residents with Alberta Health Care coverage.

British Columbia–Employment and Income Assistance (EIA)	
Administering Department	Ministry of Employment and Income Assistance
Income Provisions	Earnings exemption - $9600 yearly net employment income (no monthly maximums)
Drug Benefits	Pharmacare (prescription drugs, no deductable) Vision Care Dental Care General Health Supplements
Transitional Health Benefits	Clients leaving EIA for employment receive continued health benefits indefinitely (while living in B.C.)
Employment Supports	Employment consultation and planning Employment preparation and training Job placement services Job coaching, tools and equipment to commence employment
Reinstatement Provisions	No reference in the legislation
Benefit Rates (single person)	$906.00 monthly (2013)(support +shelter allowance) Diet assistance supplement: 40.00 monthly
Provisions for HIV Medication	HIV medication is provided at no cost by the BC Centre for Excellence in HIV/AIDS (operating from St Paul's Hospital in Vancouver)

Canada Pension Plan Disability Program (CPPD)	
Administering Department	Services Canada
Income Provisions	Earnings exemption - $4,400 yearly net employment income 3 month paid work trial
Drug Benefits	N/A
Transitional Health Benefits	N/A

Employment Supports	Personalized vocational rehabilitation supports: Vocational counselling Job development Skills training Job search support
Reinstatement Provisions	Automatic Reinstatement (up to two years from the date of employment) Fast-track re-appliation (up to five years from the date benefits ceased)
Benefit Rates (single person)	$1212.90 maximum monthly benefit
Provisions for HIV Medication	N/A

date of employment and a fast track re-application after that (Stapleton & Tweddle, 2008).

Alberta and British Columbia income support policies did not address reinstatement. Finally,

each of the four income support programs offered a variety of employment supports to

recipients. These included job training, tools and equipment, and job placements.

In sum, there were minor differences in provincial income support policies related to HIV

and employment, particularly regarding variation in rates and benefit levels. Nevertheless, these

programs were structured in a similar manner and generally provided equivalent protections and

coverage. Accordingly, they will be discussed collectively in the following sections and any

important differences reported by study participants will be noted.

As suggested earlier, study participants described a variety of experiences as recipients of

income support. These can be represented in three broad patterns. First, many recalled histories

relying fully on public income supports when they were ill and unable to work. Secondly, many

participants described utilizing flexibility within public income supports to work in part-time, contract, or casual positions while retaining partial benefits. Thirdly, several participants reported working in full time positions and relying on transitional health benefits from public income support providers. Within this context, study participants saw public income supports as both barriers and facilitators to employment and identified several important issues related to income support and employment.

8.2.1.2 History Accessing Income Supports

As suggested earlier, a majority of study participants reported having a history that included financial vulnerability and periodic reliance on public income supports. For many, this was the case regardless of their current employment status, and was often attributed to episodic illness. Twenty-three study participants (74%) reported receiving income support at one point in their adult life, most during periods of illness when they were unable to work. Nineteen of these were ODSP recipients, two were EIA recipients, one was an AISH recipient, and one had experience receiving benefits from CPPD (in combination with ODSP). The other eight participants reported no experience as social assistance recipients, some of whom had not experienced episodes of illness or who had coverage through a private long term disability provider.

Several participants discussed their tenure as income support recipients and experiences of living in relative poverty. For instance, participant 7, a straight male working full time in health and social services, recalled how his HIV diagnosis led to dependence on social assistance and financial vulnerability:

> I didn't grow up well off, but always worked, always had money, always had that power, if you will. When I got ill, I was put on ODSP, and it was a long recovery period... I didn't return to

> school, I didn't finish my degree… the decline in my income made
> me realize, this is how these people live. This is why they are ill,
> why they can't get ahead.

Other participants discussed what it was like living on the limited resources provided by public income supports. Participant six, a single mother with a university education, recalled struggling on the limited income she received from provincial income supports:

> I am privileged to have experienced being on ODSP prior to
> working. I can compare the two. It was very challenging for me to
> wait for a paycheque for finances at the end of the month.
> Because, stretching that for 30 days really takes a lot of
> management. Right, especially if you have children. Because it's,
> limited, you know, it's really, really, really hard. You know people
> think it's just a token that you're given but it's hard to manage that.
> And also, there are obviously limitations on what you can do with
> that money. Right, so it also limits you.

Participant 11, a gay male who had been laid off from his full time job in advertising, described struggling to pay for the basic costs of living:

> One of the hoops that is somewhat difficult to navigate is getting
> transportation, and it is not cheap. It is $6 for a trip. If you are
> living on ODSP and paying full market rent; do I have that cup of
> coffee today? I have had to make those decisions.

Participant 20, a full time businessmen, described drawing on income supports before finding his current position; a negative experience he had no intention of repeating.

> To survive, and to be dependent on services or assistance which
> today it is here, tomorrow I am not sure. Even in my family they
> did not know that I didn't work... It sounds so bad but again it's the
> kind of thing I would rather not disclose to my family. I finance
> myself and proudly and I'll put it this way, the amount of money
> benefits that I got from ODSP is really close to what I now pay as
> tax. So I would rather pay tax and not receive it.

Thus, experiences with poverty and dependence motivated many participants to find feasible and sustainable alternatives to living on public income supports.

8.2.1.3 Combining Work and Income Supports

In response to the limited resources provided by social assistance, many participants capitalized on the level of flexibility currently allowed under provincial disability benefits plans to engage in paid employment. Earnings exemption policies, transitional health benefits, and reinstatement provisions were policies that many participants exploited to their full benefit. As suggested by participant 11, these measures were crucial in supporting successful employment:

> Government support for people living with disabilities and trying
> to work are extremely important. Without that kind of flexibility
> from all levels of government people living with disabilities, not
> just HIV, are not going to succeed in getting back to the work
> force.

One common approach was combining part time, casual, or even full time positions while remaining on provincial income supports. This was particularly evident in Ontario where the majority of participants reported utilizing ODSP earning exemptions policies to earn extra income from part time or casual employment. This was the case for participant 17, a gay male working part time in health and social services. He described how earnings exemptions allowed him to work without completely risking his income support:

> I'm allowed to keep half my income that I make… What they do is
> they take whatever you make, they cut it in half and then they take
> that half off of your ODSP payment. So I'm still allowed to keep
> half my income, I guess you could say, until I'm making over the
> amount that ODSP would be providing me. That's restructured
> over a year's time based on the type of employment I'm on,
> because it's part time still. They evaluate after a year and if I'm
> over the amount allotted then I can apply for extended benefits.

Additionally, participant 2 described how the flexibility within ODSP allowed him to balance

working part time with University studies and simultaneously maintain access to health care

coverage:

> When I was diagnosed I got ODSP, and then I still worked.
> Basically, what you do is, you can work and then if you make
> more than you make at ODSP, they don't give you that month …
> they'll take what you make, divide that by 2 and they will take that
> and then they will give you the remaining in ODSP. So, you can
> get both. And then ODSP benefits, you get dental and you get
> prescriptions.

Several participants reported that they were earning enough employment income through the

earnings exemptions program to nullify their financial benefits from ODSP. Thus these

participants were earning an independent income while maintaining the health benefits offered

through the public income support provider. While this flexibility facilitated successful

employment, it also prevented recipients from feeling as though they were really getting ahead

financially. For instance, participant 12 was earning enough through part time work as a waiter

that he hadn't received income from ODSP in quite some time. Nevertheless he reported barely

having enough money to cover basic costs:

> I report my hours; all the hours I work here are being reported. I
> am not cheating anybody. Some months I had only for my rent,
> and my meds. I had too much money that they took all my check
> out.

Additionally, participant 17 wasn't quite sure if his part time work in a health and social services

agency was assisting him in being better off financially. He explained, "Yes, I must be

financially ahead of the game because I don't get an ODSP cheque. I haven't actually sat down

and figured out, am I further ahead with doing all this work and paying taxes instead."

As discussed earlier, maintaining access to health care coverage was a priority for most study participants. Transitional health benefits, featured in all three provincial income support policies, allowed many participants to work while maintaining access to prescription coverage and vision and dental care. For most, particularly those in Ontario where access to HIV medication was connected to employment status, keeping their prescription drug benefits was critical. This was the case for participant 3 who maintained coverage, but nevertheless feared being cut off:

> I didn't have to worry about my medication - it was covered. From my understanding also that even if they were to cut me off disability they wouldn't take away my drug card right away …but I'm not working full-time so right now, it's stable ,and I'm not going to be cut off. I still have my drug card and that's the thing that worries me the most because my partner's HIV-positive as well and his drugs are into the thousands.

Not having to worry about paying for medication was an important advantage associated with transitional health benefits. Participant 7 described the peace of mind that came with automatic coverage. He explained, "I was on ODSP with the deduction of my earnings. You know how that works. I didn't have to worry about my medication - it was covered." For some participants guaranteed access to medical coverage was so important they were hesitant to consider leaving income supports for independent work. For instance, although participant 18 felt ready for full time employment, he was not willing to risk his drug card:

> I don't know. Maybe eventually I would like to get in to full time, but I would have to really look in to seeing what their benefits are like. Because I only do part time so I can be on ODSP at the same time, they cover my meds. I would rather that than be full time and pay for my own.

Participant 3 described a similar situation:

With ODSP I have a drug card, that's how I'm paying for my medication to treat the major depressive disorder. I'm not on HIV medication so I don't have to worry about that now. I've thought about taking on more hours with my employment but then that's more that they cut me back and if I consistently make more than what they're giving me then they will eventually cut me off. I've been hesitant to do that, because I know that maybe not now, maybe not in the near future, but at some point I will need HIV medication, and the medication I have now is nothing like I can pay for. That's not a problem but when I do have to go on HIV medication it will be more expensive and I don't really want to lose the drug card because then I have that benefit whereas in my employment I don't have that benefit.

Thus, in pursuing work many participants were balancing a variety of needs including access to medication, a sustainable income, and their broader health needs. While earnings exemptions and transitional health benefits were important employment facilitators, the way they were structured often trapped participants in part time employment, and deterred them from moving forward with independent full time work, and fully pursuing their vocational goals.

An additional feature of public income supports that supported meaningful vocational transitions was the provision of automatic reinstatements. Provisions allowing recipients to return to public income benefits following a period of employment exist within ODSP and CPPD income support polices. A few study participants who were ODSP and CPPD recipients described the security they felt knowing these provisions were in place. Participant 11described the rapid reinstatement available to ODSP recipients as an important incentive to work:

It would be a disincentive if ODSP was, if you were working and cut off. For example I don't see there would be any incentive to work… Very few people are fortunate enough to get a well paying position after being out of the work force for a while. So that gives support.

Participant 31, a full time employee in health and social services acknowledged that work trials,

included as part of CPPD automatic reinstatement provisions, were an effective measure in

assisting people to engage in the labour force:

> I like what CPP did. They give you a year to go figure it out. If it's
> not working or your health is compromised then you can get back
> on. Maybe some of the provincial governments may need to look
> at something like. But I mean also I think the people need to be
> encouraged to take the lead.

Automatic and rapid reinstatement provisions were not available in the provinces of Alberta or

British Columbia; a distinct barrier for some participants. Participant 31, a Vancouver resident

described the added risk this created:

> I asked the question, "If it did not work out for me would I go back
> and be able to receive what I am receiving now on disability"?
> They said, "No." And because they said I would have to reapply it
> would be reapplying under the conditions that they are now which
> is different than when I went in 16 years ago.

In British Columbia, increased means testing has been established, making it more difficult for

HIV positive recipients to qualify for supplemental disability benefits. Participant 28 explained

how a lack of reinstatement provisions was a disincentive to work as it meant that people could

lose important protections that might not be available it they had to reapply:

> A person living with a life threatening illness should be afforded
> over and above money than what people were getting on income
> assistance. So things like water, vitamins, high protein
> supplements, all those things… They would have to go to tribunal
> they would have to develop a big case in order to get a few
> hundred dollars more which made a huge difference to people. So
> when you think about someone who has fought to put those things
> in place and then when you go back it may not be at that level… I
> have heard since then it has been harder and harder for people
> access it to have doctors signing off.

Thus, reinstatement provisions were identified by some study participants as important facilitators of employment that could help manage the risk of returning to independent employment. Among the general employment provisions included within income support policies, study participants generally described earnings exemptions, transitional health benefits and reinstatement options as the most supportive. Surprisingly, no participants reported accessing employment supports such as vocational counselling or job placement services that were provided by income support programs.

8.2.1.4 Employment Barriers within Public Income Supports

Despite the flexibility structured into public income support policies, several participants also identified barriers to meaningful employment within these programs. Dealing with an unsupportive bureaucracy, becoming trapped in the web of income supports, and feeling dependent were common complaints and caused some study participants a high level of anxiety and distress. In some cases, participants described resorting to legal supports to deal with these issues.

Several participants discussed lengthy waiting times and the frustrating bureaucracy involved in dealing with public income supports. Participant 13 remarked, "It just took a long time to get on the programme. I had to fill out tons of paperwork; so long and involved, the process." Participant 14, a full time financial services employee, described his struggle with ODSP as he was transitioning back to work after a period of illness:

> It almost took me two and a half months to get back to work,
> because they archived my file. They had to retrieve it, and find it,
> and then the communications seem to break down at that point in
> time. And it really irritated me because the anxiety started to peak
> because I was given the okay to work. I was anxious to return to
> work. Financially I needed it, and they were my obstacle ...why did

> it take eight weeks when it should have only been a two to three
> week turnaround? And there was no communication.

Some study participants described a great deal of confusion and misinformation regarding public income support policies while others acknowledged issues that arose due to the complexity of the process. For several participants, these barriers prevented effective vocational transitions, and prompted significant consequences including being cut off from income and medical benefits. For example, participant 21 recalled his sense of frustration after an administrative error at ODSP led to his suspension from the program:

> Sometimes they were very unorganized, and I am very organized,
> that's why I think I have the right to say this. There was a case
> worker and an income work specialist. So there were two people
> that you were dealing with, and sometimes I reported things to one
> person, and the other person would report to the other person. The
> other person forgot to inform the other one that I got a job, or that I
> reported. So then they just immediately send a letter saying, "You
> are suspended until you provide this and this." It was so time
> consuming. It was like working… I was wasting my whole day
> fixing a problem that was not my fault, it was their fault. They
> were not efficient, they were not organized. So I have those mixed
> feelings, it was good, but most of the time, being honest, I was
> always extinguishing fires with ODSP.

Additionally, participant 6, a university educated single mother, described how misinformation and lack of communication during a vocational transition led to her losing access to her drug card:

> I didn't understand how I would move to work benefits from
> ODSP. So, I totally messed it up. And I automatically went to
> work benefits. So I found myself paying shortfalls of, like, $800 a
> month, right. I had to literally fight, really had to make ODSP
> recognize that I needed to go back on ODSP for my meds… You
> can tell I don't really understand this stuff.

In addition, some participants discussed feeling trapped and dependent once they were on public income supports; experiences that created additional barriers and drained them of their

motivation to work. Participant 9, a gay male in his 40's, explained, "Social support services do not support people to live, and help you get off social services. They keep you pulled down." Participant 6 also described how her dependence on income supports led to feelings of exclusion. She remarked, "The whole idea of disability and going on a provincial handout, it sometimes feels like you're being put out to pasture. Like you're just shuffled off... There is no support there. It's zero." For other participants, the dependence and exclusion they associated with public income supports created barriers to employment that were as difficult to overcome as the physical illness they experienced as part of their disease. Participant 7 explained how a brief period as an ODSP recipient threatened his mental health making it difficult for him to summon the motivation to work:

> I was actually not on ODSP very long, a couple of years… But
> sometimes you get sicker on disability, and it's not a physiological
> sickness. It's just you feel sick. You feel like, well this is my label,
> and this is my life, and you gotta break out of that mentality. It's
> very self defeating.

Participant 21 recalled how his experience as an ODSP recipient eroded his self esteem and instilled a determination to work:

> I felt ashamed every time I had to visit one of the ODSP offices
> and waiting in those rooms. I felt really bad and very small… I was
> like what am I doing here? That is one of the reasons that makes
> me really work hard and saying I want to get out of this. This is not
> for me.

In some situations, barriers remained even after recipients had transitioned successfully to employment. Many participants valued the opportunity to work, however they also reported a high degree of vulnerability and fear regarding being cut off of income supports should they make too much income from employment. Thus, for some participants, success in employment

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often meant risking their security. Feeling trapped in this manner was a dilemma reported by

participant 3, a young gay male with aspirations to develop a career in the transportation sector:

> Well, the only risk that I see is I kind of rely on the disability
> income. I relied on it before and now I'm working I still kind of
> rely on it because I'm still getting some from them on top of what I
> am getting with my employment. However, the risk that I'm
> fearful of and I spoke about with my worker is… what if they cut
> me off come June. Then July and August I'm not working and so
> how am I supposed to support myself with no income not even
> from disability… she assured me that if I was consistently making
> more than what they gave me then I would be cut off.

Additionally, several participants noted gaps in public income supports that were critical barriers

for those working and living with an episodic illness. For example, despite the existing flexibility

in the ODSP program, there are also penalties for those with fluctuating illness. One important

gap involved a lack of accommodation for illnesses of longer than a month. Several participants

who were combining work with ODSP described feeling very vulnerable should they be unable

to work for a long period of time due to health reasons. This was particularly the case for

participants in precarious employment or those working part time or casual positions with no

sick leave or short term disability. Participant 2 worked part time with no sick leave. He feared

losing access to earnings exemptions and having to go back to full benefits if for some reason he

were to become sick for a month and was unable to work:

> When something gets too stressful or you need to take some time
> off, because, you know, there have been times where I have taken,
> like, a week or two weeks off because, things do seems to get a
> little overwhelming… So, ODSP will cover that. The maximum
> you can take off is a month and then they'll cut you off and then
> you have to go back.

Participant 1explained a further gap that occurs due to the current practice at ODSP of

calculating recipient claw backs based on their history of monthly income from employment.

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> If you lose your job, or if you find yourself out of work due to
> health reasons there is going to be a month where you are not
> having any income from your previous source of employment and
> they are still going to be clawing you back for the month previous
> so there is going to be a gap month where you have almost no
> money. If you are in a situation where you are paying market rent
> you could find yourself in a trouble pretty quickly.

Lack of coverage for longer periods of illness is an essential gap for any recipient who is living with an episodic disability. For those participants who rely on ODSP for their drug card and subsequent access to HIV medication, being cut off of income support could also mean an interruption in their treatment. These particular gaps in ODSP coverage existed as barriers and contributed to the risk participants assumed in taking on paid employment.

A final barrier reported by a few participants concerned the lack of integration between jurisdictions and income support programs. Some participants reported accessing CPPD in combination with provincial disability income supports. Unfortunately, fragmentation and lack of communication between the federally run and provincially run programs means that people fell between the cracks. Participant 14 described just such a situation:

> I wish I had never applied for CPP. I didn't realize I had the option
> of not. Because long term disability was a tax free benefit, CPP
> isn't. This year, my taxes have gone up, skyrocketed. So,
> technically I only made maybe twelve or thirteen thousand dollars
> this year, but because I got a lump sum payment that covered me
> for a long back dated time my tax bracket's gone up to twenty
> eight thousand dollars. That caused me to have an over payment
> with my ODSP, all this kind of stuff. When I came to that, they
> washed their hands of me. They told me I had to basically, deal
> with it on my own. Because once I was receiving CPP, I was
> receiving more than I would have received from long term
> disability. So, long term disability was wiped off.

8.2.2 Access to Treatment

Access to HIV medication was a critical priority for all study participants. In the absence of a widely available cure, pharmaceutical treatments remain a life saving option for those living with HIV. A range of issues related to the ability to access affordable HIV treatment and medication was identified by many study participants. Generally, treatment was seen as an employment facilitator as it allowed most study participants to feel healthy enough to be in the workplace. Nevertheless, access to affordable treatment was not guaranteed for all participants, and some struggled with maintaining access. As discussed earlier, several participants reported sacrificing their vocational goals in the interest of maintaining stable and reliable access to free HIV treatment. This was particularly the case for participants in Ontario where HIV medication was dependent on employment status. The experiences of these participants will be contrasted with those from provinces where medication was free and more universally available.

8.2.2.1 A Summary of Access to Treatment Policy

Prior to describing participants' experiences accessing treatment, a brief summary of Canadian policy related to this topic will be discussed. Kort and Ragan (2008) define universality as a state of affairs whereby "… all residents of the relevant jurisdiction are eligible for the catastrophic drug program on uniform terms and conditions that do not place an unreasonable cost burden on individuals" (p.7). Through the Canada Health Care Act, all Canadian citizens have access to universal publically insured health services including hospital services, physician services, and inpatient pharmaceuticals (Kort & Ragan, 2008). Unfortunately, there is no universal coverage for prescription drugs in Canada. Access to pharmaceuticals is a provincial responsibility, and every Canadian province and territory offers a program for subsidizing the cost of medications (Canadian Working Group on HIV and Rehabilitation, 2011). The eligibility criteria differ from province to province and considerable inequities exist in

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access to prescription drugs across Canada (Kort & Ragan, 2008). Generally, the cost of obtaining HIV treatment depends on where you live, your level of income, and whether you have access to insurance. As there is currently no widely available cure for HIV, the standard of care treatment is a 3-4 drug combination which must be taken indefinitely (Brown, 2001). Consequently, the monthly cost of these medications can easily reach over $1,500 and are frequently over $20,000 yearly (Brown, 2001).

In British Columbia, a province with 4.11 million people, there have been a variety of initiatives aimed at providing universal access to HIV treatment (most recently under the guise of treatment as prevention) (Kort & Ragan, 2008). Consequently, HIV medications are distributed at no cost to eligible HIV-infected individuals through the Drug Treatment Program at the BC Centre for Excellence in HIV/AIDS (Stapleton & Tweddle, 2008). Reportedly, over 4,000 HIV-positive British Columbians currently receive treatment through the Centre from an outpatient clinic located at St. Paul's Hospital in Vancouver (Kort & Ragan, 2008). A similar situation exists in Alberta, which has an approximate population of 3.29 million people. Here, universality is also a goal. HIV medications are dispensed free of charge through the Northern and Southern Alberta outpatient HIV Clinics to all Albertans living with HIV (Kort & Ragan, 2008). This is the sole point of care for HIV treatment as these medications cannot be prescribed by general practitioners.

Pharmaceutical drug coverage is managed differently in Ontario, a province of 12.16 million people which saw over 40% of all positive HIV tests in Canada in 2011 (Kort & Ragan, 2008; Public Health Agency of Canada, 2009). In this province, HIV medication is cost shared between public funders and employers. The Ontario Drug Benefit program offers drug coverage to Ontario residents who are beneficiaries of the Ontario Health Insurance Plan (OHIP) and

recipients of social assistance programs (Kort & Ragan, 2008). Otherwise, individuals must rely on group coverage provided by an employer. Supplemental catastrophic drug coverage is available through the Trillium program to Ontario residents who have high prescription drug costs in relation to their net household income (Stapleton & Tweddle, 2008). Thus, Trillium exists as a back up for individuals who either are not recipients of social assistance, do not have OHIP coverage, or whose employer does not provide prescription coverage (self employed, part time employment, contract workers etc.). The program provides 100% coverage for prescription drugs once a means-tested deductible has been reached (Stapleton & Tweddle, 2008). On average this deductable tends to be approximately 4% of annual household income (Kort & Ragan, 2008)

8.2.2.2 Treatment Access: The Ontario Context

As suggested earlier, Ontario is one of seven provinces in Canada that does not endeavour to provide universal access to HIV treatment (Kort & Ragan, 2008). Prescription drug coverage for employed individuals in Ontario was assumed to be primarily an employer responsibility and a variety of means tested public insurance schemes were in place where gaps existed. While this treatment access system has often worked well for most long term social assistance recipients (Chapman, 2006); at times it was identified as a barrier to employment by those study participants interested in working or involved in a vocational transition. While many study participants in Ontario valued access to free or affordable HIV medication, others fell through the cracks while transitioning into employment. Participant narratives revealed a patchwork approach to treatment access in Ontario; one that saw some participants risking access in order to work.

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Due to a critical need for access to HIV treatment, several study participants in Ontario were hesitant to risk a vocational transition that jeopardized their access to drug coverage. The prohibitive cost of heavily patented HIV pharmaceuticals was a broad social and political issue that concerned several participants and caused personal anxiety. Although Participant 1's medication was covered through his employer's group insurance he remained worried about the high costs associated with HIV drugs, "The only final thing is the cost of meds. Like, to me, that's a crime, what they're doing with the cost of meds. That, I have to say, I think is criminal."

Some participants who were combining part time work with income supports worried about the high cost of medication and were hesitant to risk their current coverage for full time work. Several participants feared that, even with full time employment, they would not find themselves in a position to afford the medication that they are so dependent on. Even though participant 3 was not currently taking HIV medication, he worried about the future costs of treatment, stating, "At some point I will need HIV medication and the medication I have now is nothing like I can pay for. That's not a problem but when I do have to go on HIV medication it will be more expensive." For many Ontario participants this meant remaining on ODSP indefinitely in order to continue to access free HIV medications. Other participants feared taking on full time work for fear that the employer wouldn't offer drug coverage or that they would be denied access to the plan. Participant 18, who was co-infected with Hepatitis B and Hepatitis C, carried the burden of needing medication for several illnesses. He articulated the dilemma many others faced "I need to be on disability for my medication. Like if I started full time, I don't know how I would be able to afford my $76,000 medication a year." Participant 16 was able to work full time as a waiter and have his medication covered through a supplemental plan. However, due to the high costs of his HIV drugs he worried about being viewed as a liability to

future employers and never holding a position where he could access benefits. He explained, "The benefit packages for some of these medications for HIV, for cancer and other diseases are outrageously expensive. I mean the pharmaceutical companies are sucking you dry, pretty much." These fears existed despite the fact that transitional health benefits were available to ODSP recipients who were working without employer provided drug coverage.

A few participants reported encountering barriers when navigating the treatment access system in Ontario. Lack of integration in the system caused serious problems for a few participants who despite being employed, fell through the cracks, and were unable to access or afford their HIV medication. In each case, these situations emerged while participants were engaged in vocational transitions where they were moving from one treatment provider to another.

Three specific problems described by study participants highlighted the inequities in the access to treatment system in Ontario. In the first example, participant 6 described leaving ODSP to work full time for an AIDS service organization that did not provide drug coverage. The single mother was not provided with benefits counselling or adequate information, and so was unaware that she could maintain access to transitional health benefits while working. She subsequently lost access to treatment altogether due to the complex bureaucracy and misinformation that surrounded her transition to work. The mistake was eventually identified and resolved with the help of a health care professional but not until after she and her family had suffered serious financial consequences. She described the toll this situation exacted:

> All through my pregnancy, like, for six months, I was buying my own medication. I'm talking about at least $3000 a month. So, I emptied out my savings up to a point when my Dad would send me money from Africa. He would sell cattle and send me money for my medication. I was finally rescued when I was in hospital

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delivering my child. My doctor was like, "Oh, OK, so we'll need
to change your medication because you're no longer pregnant.
This is what you're going to take." And I found myself
negotiating to get the type that is cheaper. She asked me why, and
then I told her. And then she hooked me up with somebody,
right…

In a second example, Participant 22 described relocating to Ontario from another

province where he had been receiving universal access to HIV medication. In Ontario, he worked

full time for a private sector employer who did not provide prescription drug coverage.

Unfortunately he also didn't quality for catastrophic drug coverage under the Trillium program, a

situation which caused him financial hardship and threatened his health. He explained how

systemic problems and the financial burden of paying for his own medication eventually forced

him off treatment:

> The year before I made so much money I didn't qualify for
> trillium. So I had to come up with the money and try to work it
> thought the pharmacy so I could pay for and get more. The
> pharmacy was pretty agreeable to do payment plans. But then I got
> $3000 behind. I just couldn't afford to pay them so I ended up
> going off my meds.

For HIV medications to remain effective they require strict adherence, otherwise the virus can

mutate and develop resistance to treatment (Thaczuk, 2009). Thus, continued and uninterrupted

access to HIV medication is critical. For participant 22, when he no longer had drug coverage

support, there were serious health consequences related to stopping his treatment:

> In this year, I've messed up with my medications, mutated my
> virus, so now the meds I'm taking are not working. I have a viral
> load again. This is all because of that year. … That messed up year
> has had an impact on my health. But it was only an impact because
> I lived in Ontario. This never would have happened in
> Saskatchewan or B.C.

In a third example, participant 24 described her experience accessing HIV treatment through catastrophic drug coverage provided by the Trillium program. As a self employed individual in a small business, she and her husband did not qualify for transitional benefits through ODSP, nor did they have the resources available to engage a private health insurance plan. Her experience highlights several problems reported by those relying on the Trillium program. Despite existing as a resource to assist people with prescription drug costs, the Trillium program cost this participant thousands of dollars and contributed to her decision to cease treatment. In this case, she explained how the high deductible amount required by the Trillium program caused undue economic hardship for her family:

> I'm not on any drugs now, but the first year, I think between the two of us we spent you know more than $20,000 on drugs. My credit cards are still maxed out, because fortunately I have piles of credit cards.

In addition to having to go out of pocket for drug costs, this participant described the sense of frustration she felt when trying to submit claims to an unresponsive bureaucracy:

> We send in receipts, and we don't hear from them, or they only cover half of them…They say that we need to have verification from the pharmacist that you actually paid for it... Then a month and a half later I call and I say okay, "What's the problem"? And they say, "Well we need verification that you actually paid for it and not somebody else." And like, what the fuck, who else is going to pay like $1500 a month for drugs for me? I don't understand, what is that all about? And you know some of it is still not resolved… I've just started screaming because it hurts the stuff that they say.

As noted earlier, participant 24 eventually went off of her medication against her doctor's advice. While she did not directly attribute this decision to her experiences with the Trillium program she was reportedly relieved to not have to continually expose herself to this kind of frustration.

While only reported by a small minority of participants, these three specific examples emphasized systemic problems that existed within Ontario and reinforced a reluctance to transition to other forms of employment. Additionally, these narratives demonstrated a lack of integration among Ontario's public income supports that made it difficult for participants to move easily from one payer to another. Unfortunately, it was those participants who were trying to access full time employment or improve their vocational options who reported significant gaps in coverage that jeopardized their treatment. Those participants who remained on ODSP rather than risking other forms of employment reported the least amount of difficulties accessing medication.

Participants who worked full time for employers who did not provide prescription drug benefits also identified a range of barriers connected to their participation in the Trillium program. Again, although it was designed as a resource for those who were struggling to pay their prescription drug costs, the Trillium program often caused financial hardship. Several participants in Ontario reported having no choice but to rely on the Trillium program if they wished to remain in the full time workforce. Unfortunately, having to pay high deductible costs, long waiting times for reimbursement, and gaps in coverage undermined many participants ability to work successfully.

A common issue identified with the Trillium program was related to paying program deductibles. As part of means testing to establish eligibility for the Trillium program, participants were assigned a yearly deductable amount. This amount has been reported to be, on average, 4% of household income (Kort & Ragan, 2008). Nevertheless, many participants reported that paying their deductable was financially difficult as was Trillium's policy of requiring recipients who are working to pay for their medication before being reimbursed. Similar to participant 24's

experience, participant 1, a full time government employee, described struggling financially

while he waited for reimbursement from Trillium:

> You have to pay your insurance first, and then you have to get your
> receipts, and then send them in to Trillium, and then you have to
> pay your deductible from Trillium. Which - mine is $1,600. So
> that's like 3 months. Then the fourth month is when I'm due.
> That's when I'll get a rebate, if you will, from Trillium. But it will
> be the sixth or the seventh month before I see it because of
> processing time, so I have to pay the $650. And that is - it is a lot
> of money.

Participant 22, a full time employee at an AIDS service organization, described how Trillium

deductibles and delayed reimbursement caused one of his colleagues to accumulate a high level

of credit card debt, an issue that forced her off of HIV treatment:

> There is a woman here who is off meds for a year now. She ran out
> of money on her credit card. I mean she gets paid back every
> month for the meds, she did. But the payment came at the end of
> the month so she got charged interest every month. So she put the
> money on there, so every month she was down okay maybe 100$
> or 50 $ or whatever. But you do that every month over a couple
> years and you're in the hole.

Participant 8, a full time financial service employee, also reported difficulty paying Trillium

program deductibles:

> Because you're working, you don't have the benefits to properly
> buy all the medications, so you got to go to Trillium. So that's a
> setback… I pay close to $800 per year or something like that. It's
> based on a percentage.

Due to the variation in his income, participant 16, a full time waiter, struggled with the

deductibles, although he also acknowledged that that the situation would be significantly worse if

he couldn't access the Trillium program:

> There's a deductible that you pay based on income. I think for the
> average person it's a couple hundred bucks every few months or

> so. It makes it much more easier cause without that you would be
> paying upwards of a thousand dollars a month

It is also important to note that the Trillium program only provided catastrophic drug coverage.

Gaps in vision and dental care existed for those who had no employer benefits. This meant that

those who remained on ODSP instead of transitioning to full time employment often enjoyed

more substantial benefits coverage; an additional disincentive to full time employment. This

additional barrier was described by participant 20, a full time employee in the private sector:

> I think the major part is about the benefits, I think that some people
> might find them tricky or problematic… Another issue I was
> exposed to recently is that some of the medication cause some
> dental problems and acidity in the mouth and other things. It
> causes some teeth problems, most of the things are not covered by
> the insurance policies. I know people who lost a tooth and cannot
> afford an implant, a single implant is about $3000, it is something
> not affordable. If there is any way to make improved policies it
> would be a blessing.

Thus, despite existing as a supplemental benefit to provide catastrophic drug coverage for those

who received no benefits through their employer, the Trillium program often erected new

barriers for some study participants to manage.

In sum, participant descriptions of Ontario's treatment access policies reveal a patchwork

of programs designed to supplement employer provided drug benefits. Those who combined

ODSP with work often did so to maintain access to stable prescription, vision, and dental

coverage. Many participants reported gaps in coverage and multiple barriers associated with the

lack of universal coverage in Ontario.

8.2.2.3 Access to Treatment: The Alberta and British Columbia Context

As indicated earlier, five Canadian provinces provide near universal coverage of HIV

medications (Kort & Ragan, 2008). This was the case in Alberta and British Columbia, the two

other jurisdictions represented by participants in this study. In contrast to Ontario interviewees, participants in Alberta and British Columbia described very few employment barriers related to access to treatment policies. All study participants in these jurisdictions reported receiving their HIV medication through an outpatient clinic, regardless of whether they were employed or not, and unconnected to their current employer. For these participants, access to medication was something they did not worry about. For instance, participant 28 described how he accessed treatment in British Columbia:

> If you are HIV positive, you can receive your meds covered; paid for. To the best of my knowledge it's through the Center of Excellence here in Vancouver, at St Paul's Hospital. The medications are covered, and really it is like thousands of dollars a month… Oh my God, how could you otherwise afford something like that, as an individual, as a person who was not covered? It is a Godsend really. I mean, if you are going to be HIV positive, really seriously, B.C. is the best place to be in that regard.

Participant 23 described a similar approach to treatment access in Alberta, one that he was equally appreciative of:

> Alberta health care covers it, so I don't have to worry. I think in Alberta we're quite lucky because they pay for the medication…. basically Alberta health care covers the costs so the government basically pays for the medication. I think my medication is about $1600 a month, so that is covered… You have to see a doctor every three or four months and there is a pharmacy in the clinic. That is where you get your medication from, once a month, and then manage it to make sure that you are doing all the right things. … I don't need to worry about it. It would be horrendous, I can't even imagine how people could manage that on top of their regular life stresses.

When discussing access to medication in these two provinces, there was general consensus among participants regarding the general advantages that a universal policy provided.

One participant reported that he receives universal access to medication despite his status as a temporary foreign worker. This provided him a deep measure of security as he would not have received this level of access in his home country. Despite several unknowns regarding his future and some uncertainty regarding his immigration status, he felt secure knowing that access to HIV medication was assured as long as he remained in the province. This assisted him in maintaining his health despite working in a vulnerable situation.

Participant 22 had relocated from a province that had a universal approach to treatment to pursue a full time position in Ontario. He was able to compare policies, and identified several benefits associated with the model adopted in Alberta and British Columbia. One specific benefit he identified was that it decreased disclosure risks for people living with HIV in the workplace. Since their meds were provided free by a third party, fears related to involuntary disclosure and discrimination in the workplace were minimized. He summarized his fears about his situation in Ontario:

> In BC you go pick up your meds, then go home. In Ontario, you give them your medical card - which your employer has access to - and then they give a list of all the meds you take. Now really the employer doesn't get that because of confidentiality. But with the new employee, at the end of the year and the rates have gone up significantly, and you know that at $1500 a month the average non HIV positive person doesn't take medication to that extent. So if there is a new employee in the company, and a sudden jump in medication costs, there is a chance that it could be found out. And it made me really uncomfortable.

Participant 30 also acknowledged that receiving medications through an outpatient clinic provided him with some comfort and protection from being stigmatized at work. He indicated a clear preference to not have to access treatment through his employer:

> I'd feel kind of weird, if that was the case, if I had to go through my employer. I would feel, I don't know, it would be hard for me

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to do that actually. I am concerned about who knows about my
HIV status just because of my work. Also, like I said, back in the
late 80's early 90's I was stigmatized. It kind of leaves you more
cautious and rightly so. It makes me angry at the same time and I
go out and talk to students and get angry about it, but I kind of
separate it still.

Generally, there were very few complaints or criticisms regarding treatment policy in Alberta or

British Columbia. The only reservations expressed related to accessing medication in limited

settings. For participant 29 this was more an inconvenience than a barrier:

> The biggest sort of hurdle is that every 3 months I have got to do
> my blood work. I have to see the doctor to get the prescription, and
> then I have to come to St. Paul's and pick up my meds. That's the
> hurdle, every 3 months it has to be done, then once every year I
> have to make sure my blood work order is in place. So, compared
> to a lot of other people or places it is probably much easier. But it
> is still a little hurdle that I have to make, and my doctor can be
> hard to see. So I have to know, I have to look at myself; okay in
> another month my meds will be running out, time to start making
> appointments. So I have to stay on the ball and stay on top of it, it
> doesn't just happen I have to be on it.

Among several participants with experience in Alberta and British Columbia, there was

recognition that universal access to treatment was an important principle that provided them with

specific benefits. Several advocated for more equitable access to treatment across other Canadian

jurisdictions. This was the case for participant 22 who had relocated to Ontario only to find

himself without access to medication. He expressed the need for change:

> Having money change hands for meds just shouldn't happen,
> especially for long-term, life saving, medicine. Money should stop
> being part of Canadian health care. Maybe I got spoiled in B.C.,
> but I just don't get how it works here. Obviously, it is a very
> money focused environment. It's all about the money, it's all about
> the profit, all about making sure everyone gets paid. But I don't
> think that health care should be part of that little dance.

Participant 22, also commented on the inequities within Canadian access to treatment policy:

> I would think that the medication piece is probably the biggest burden that people face and they end up not getting their medication. I am sure there are a lot of people who don't have access to medication because they can't afford it and that scares me. From a societal perspective it doesn't seem right, or fair, or just. It doesn't seem right that, in Canada, just because I live in Alberta I can get my medication paid for, but if I lived in Ontario I'd have to pay for it myself until I became bankrupted. That doesn't seem very fair. On a federal level I would suggest that there has to be someone looking at this because it doesn't seem right. I think anyone with HIV should be treated the same way whether they're in Alberta or the Yukon.

While none of the participants commented on it, of the eight participants living in Alberta or British Columbia, only one reported part time or precarious employment. Most participants were in stable full time employment for a minimum of five years and none reported still being on income supports.

Hence, access to HIV medication was important to all study participants. Even those who reported not taking HIV medications were concerned about issues of cost and access. Policies determining access to treatment varied provincially, with Alberta and British Columbia favoring a universal approach while Ontario followed a strategy of providing mean tested, supplemental coverage.

8.2.3 Housing Policy

A secondary, but important social policy factor influencing participants' employment trajectories was housing policy. A lack of affordable housing coupled with often inadequate housing supports meant that participants, despite their employment status, often struggled with housing costs and access to safe and affordable housing. A substantial network of social housing providers exist in Canada to support people living with HIV and their diverse housing needs Unfortunately, many participants reported losing access to housing subsidies and supportive

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housing when they found employment, a factor that served as an employment barrier. A lack of integration between housing and income support policies meant that participants often fell through the cracks during vocational transitions.

Safe and stable housing were among the many losses participants attributed to their HIV diagnosis. Several participants described losing their housing following an illness or diagnosis with the disease. For instance, a combination of episodic illness and unemployment meant that participant 3 could no longer afford to live independently. He explained, "I became unemployed before I started working for the staffing agency, and I ended up moving back in with my parents." Participant 1, a federal government employee, recalled a slow progression of housing losses due to episodes of illness and related unemployment:

> I used to own a house in East York and when I was diagnosed, the
> last thing I could do was look after the house. I sold it. Then I
> rented a townhouse and I thought why am I spending $1300 a
> month rent to somebody I don't even know. So then I went and got
> a basement apartment in Scarborough, where I grew up… not
> realizing just how drastically it had changed. I had to get out of
> there.

Participant 13, a financial services professional, also struggled to maintain his housing during a long episode of debilitating illness, a period where he was unable to work:

> I went from my condo to a rental and came to a point where I
> couldn't afford the rent. It's simple. I was getting close to an
> eviction, and I didn't know what I was going to do at that point.
> I've never been evicted, my credit rating was spotless, and I asked
> at that point in time like, what can I do? I've been served this
> notice and I have this much money. I have a lot of pride and don't
> like to go to my family.

Some participants reported living in subsidized housing, an option that provided them with increased stability and financial security. Unfortunately, several of these participants in all jurisdictions, reported losing access to these subsidies during vocational transitions to improved

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employment options. Frequently the loss of a subsidy eroded any financial gains they may have made through employment. This was the case for participant 28 who explained, "The difference of returning to work has made me sometimes only a few hundred dollars, financially because of not having a [housing] subsidy anymore." Participant 29 described the sizeable increase in rent he faced after returning to full time work and losing his housing subsidy. He recalled, "So when I returned to work and because I was full time employment so my rent went up by $800. So it became market rent. I was like I am not paying market rent to live here right"?

The prospect of losing their housing subsidy was one that was weighed by several participants as they considered transitioning to full time work. Participant 28, an AIDS service organization employee, recalled feeling secure that his new position would afford him enough income to afford market rent:

> I was ready. It was kind of scary, but I also knew I was bringing
> income in. So I could pay for where I was living which was nice.
> But yeah I had a bit of fear… but it was just like I was willing to
> just walk right through it, open that door at least take a shot.

For others the risk associated with losing their access to subsidized housing was a factor that made them hesitant to attempt full time employment. Participant 12 discussed his reluctance to attempt full time work:

> If I have a full time job… that is my fear, to have money, because
> then I have to pay the full rent; $700.00 plus my expenses. Am I
> going to find a job for at least $1300 a month? That is another fear
> I have.

In response to this fear, participant 28 discussed the importance of portable subsidies that would allow people living with HIV more choice over their housing options.

> I had a housing subsidy but it was not a portable housing subsidy. So whereas if you have a portable housing subsidy you can choose where you wish to live… If you get these housing subsidies for people, they are in the little AIDS buildings. I think you need to give people subsidies where they can use it anywhere where they want to live. I think that would cut down on the stigma and also the hopelessness

8.2.4 Stigma and Discrimination: Societal Attitudes about Work, Poverty and Income Support

Similar to other components in the ecological framework, the stigma and discrimination that surround HIV was also connected to issues of public policy. Study participants described a broad range of dominant societal narratives about work, poverty, income support, and entitlement that surrounded the discourse on public policy. Within their transactions with systems at the public policy level, many participants described stigmatizing assumptions and social judgments associated with poverty and income support. These widely held societal beliefs influenced participants' employment trajectories and experiences engaging with social supports. Indeed, for some participants, the persistence and determination to work may in part be shaped by a recognition and endorsement of these stigmatizing narratives.

Participants described the stigma they faced as people living with HIV and income support recipients. In part, this stigma was based on a range of widely held assumptions and societal messages that viewed income support recipients as unworthy and undeserving. For instance, participant 13, a part time waiter combining work and ODSP, described his treatment at the hands of co-workers who accused him of cheating the system:

> He was screaming at me saying, "You have guys taking my money that I pay for taxes right"? … Yes but I report my hours, all the hours I work here are being reported. I am not cheating anybody… I called him 4 or 5 times telling him, "You make me feel uncomfortable, not because I don't want to work, it is my situation and my health. Not because I don't want to work, I am sorry about your taxes. I don't want to hurt you at all, but it is the way I am,

the way HIV is. That is why sometimes it does not allow me to
work, that is why I do not have a full time job. That is why I
cannot even have a part time job"…

In addition to the workplace, these sorts of judgments were reported as being common within

important social networks such as families and communities. For example, participant 5, a single

mother, described how similar values were reinforced by her children.

But as my daughter says, "Mom unless you're almost gonna kick
the bucket, I am not sure why are you going to take benefits that
you don't really need. Your still a healthy person, just get out there
right." So as much as I try to not let her dictate my life I just keep
going right.

Furthermore, a few participants reported the social stigma they faced as social assistance

recipients in the gay community. For instance participant 21, a gay male and a recent immigrant,

described his experiences when socializing:

I was ashamed of saying I lived from ODSP… I got discriminated
against, like socially, right. It is a tough world out there, being in
the gay community. That was really mean.

This was also reported by Participant 30, who described the effect these judgments had on his

self esteem:

People on low income… they are stigmatized by association. You
become, unfortunately, stigmatized and it's hard on your self
esteem. It's really hard on your self esteem. The gay community is
unfortunately not the most supportive place sometimes…
Unfortunately people judge you by who you are, what you do,
what you look like, where you live. They size you up in like 30
seconds right?

Some study participants described a range of feelings they had internalized as a result of

their experiences with income support and associated social judgments. Several described the

shame they felt at the prospect of depending on income supports for a living. This was the case

for participant 29, a gay male, who explained, "For me, when I was on assistance it kind of feels

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like you are not contributing you are taking away." Participant 14, a gay male and recent immigrant, described how he felt when living on income supports and having to utilize practical and support services.

> Food banks; it was very embarrassing. Maybe my pride had taken a hit because I've been in the gay community for so long; I have a lot of connections. I know a lot of people. I've worked, I've volunteered, even when I was working. To go to a food bank and face the people that I've actually worked with, or collaborated with, it was a little bit embarrassing. It took away my pride and my self-esteem. I began to hate a lot, and I don't use that word a lot, at all, really. It's very strong. But I became to hate myself and hate the system. I became a very negative person because I was restricted from doing things.

In addition to shame and embarrassment, some participants described battling feelings of unworthiness they associated with having a disabling illness and being on income supports. Participant 7 explained, "Because I think that's the stigma of being on disability. You may be healthy enough to work but you don't feel you're worthy of work." This was also the case for participant 9 who struggled to deal with similar feelings of unworthiness. He acknowledged, "That also ties in to my recovery as well, getting to the point where I am beyond thinking I am not worthy, and actually I am worthy."

Personal struggles notwithstanding, many study participants reported negative feelings with respect to other social assistance recipients. Having successfully sustained employment, several participants directed a range of social judgments towards other people living with HIV who continued to be on income supports. Perhaps unaware that they were perpetuating stigma, some participants were so convinced of the positive value of work in their own lives that they judged other people living with HIV who weren't working. For instance, participant 2 judged his friends harshly despite the fact that he also continued to collect income support from ODSP. He

explained, "I just have to be honest with you, I have friends that just sit home and collect

ODSP... I just don't think its right." Similar sentiments were expressed by participant 24 who

resorted to assumptions about others' health based on their appearance:

> I think it's much better to be employed than not be employed… I
> just really wonder what's going on with those guys that seem to be
> really healthy, that don't work, and I just think, "Are they really
> bored? What are they doing"?

In an additional example, participant 26, a gay male working full time in the hospitality industry,

expressed his feelings about others he felt weren't entitled to collect income support:

> I have to be pretty desperate to go on public assistance. It is
> something that doesn't resonate with me… I don't want to say this,
> I have met a few people lately that are on disability who are
> probably stronger and more able than I am and it bugs me… Sure I
> can get a doctor's note, I could milk this one but I don't want to sit
> at home collecting benefits. There are other HIV positive people
> that are collecting disability that I don't believe should have it, and
> it pisses me off actually. I am able and the last thing I want to do is
> live off the public. I know some people have a real problem with it,
> I do.

At times these judgments were perhaps connected to participants' own deeper feelings of fear,

frustration, and anger. Acknowledging his own fear of becoming a victim, participant 14

described income support recipients as undeserving of income benefits:

> I look around at these individuals that are only collecting ODSP,
> who are crack addicts, drug addicts, alcoholics… I don't want to
> become a victim, and that's what I hear from these people. That
> they're always saying, "Well I deserve this, I deserve that, but I've
> done nothing to get it.

Additionally, Participant 15, a straight male working as a laborer, described his resentment in

seeing others receive benefits he had not been able to access:

> I am working very hard. I want to work, I like to work, and I like
> to make money. I am talking about myself, but I know many men
> who have HIV who do not like to work… I don't know how they

> do it, but they have housing from the government. Years and years
> ago they did not call me, and they get the housing, so they only pay
> $200 rent and ODSP gives them $1,200.00. They live very happy
> with that. But it is not my case, it is not my case.

Thus, stigma and discrimination often surrounded participants' interface with income support

policies and impacted their sense of identity and the way they viewed other people living with

HIV. In particular, study participants described a broad range of dominant societal narratives

about work, poverty, income support, and entitlement that shaped their experiences as income

support recipients and workers.

8.3 Chapter Summary

This chapter discussed public policy; the sixth and final major category in this framework. The

national and provincial laws and policies that shape and impact labour force participation for

people living with HIV were described including income support policies, access to treatment,

housing policy, and stigma and discrimination. This chapter completes the presentation of the

results. The next chapter concludes the study and contextualizes the dissertation. This will be

accomplished by discussing the findings in relation to previous research, identifying the

implications for vocational theory, and describing the contribution to policy, practice and,

service development.

CHAPTER NINE: DISCUSSION

9.1 Introduction

The purpose of this study was to develop a conceptual framework identifying the important processes and structures that shape the successful labour force participation of people living with HIV in Canada. As discussed earlier, this study drew upon grounded theory and community-based research methodologies in exploring the following questions: 1) What are the perceived benefits, risks, challenges, and facilitators of labour force participation from the perspective of people living with HIV who have successfully returned to the workforce and remained employed?; and 2) What are the perceived benefits and challenges of community vocational rehabilitation services in assisting people living with HIV to return to the workplace and maintain employment from the perspective of people living with HIV? Furthering understanding in one's professional field is one of the primary goals of conducting social work research. Creating applied knowledge that contributes to vocational service development for people living with HIV was a guiding principle of this community-based research study.

Some of the results of this study support established ideas that have been previously documented in the research literature on HIV and employment; however, in several areas findings provide new insight and can further inform community vocational service provision for people living with HIV. It is hoped that the conceptual framework presented as part of this dissertation will contribute to the discussion about labour force participation for people living with HIV in Canada, and assist researchers and community service providers in further considering the ecological contexts influencing this phenomenon. The following chapter is intended to integrate the findings of the current study with the existing literature, while also extending the dialogue to propose some broader ways of conceptualizing HIV and employment

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in Canada. Accordingly, this discussion will focus on specific areas of contribution to the current

theoretical and empirical literature on HIV and employment and will highlight their importance

for organizations and social workers providing services to people living with HIV.

9.2 A Summary of the Work in Progress Conceptual Framework

Findings from this study suggest that, for many participants, working successfully

involved a series of vocational transitions that comprised a reciprocal transaction between

personal vocational development and environmental structures. Due to the diversity of the

sample, unpredictable disease progression, and the complexity involved in working successfully,

there was no single or linear pathway to vocational success. Consequently, although other

sensitizing theories were considered, an ecological perspective was seen as best able to

synthesize and integrate the participants' varied experiences of living and working with HIV.

The rationale for this approach, established in earlier chapters, centres on a parallel focus within

ecological perspectives on both the environmental and policy contexts of behaviour as well as

psychological constructs (Sallis et al., 2008). The following framework, (Fig. 9.1) emerged from

the study data and is offered here as a means of conceptualizing the study results.

There are six main categories that form this conceptual framework and explain the data as

they emerged from the narratives of research participants. At the centre of the framework are two

main categories that constitute the psychosocial processes involved in working successfully:

Intrapersonal Processes and *Interpersonal Processes*. Each of these connecting categories

contains a number of subcategories; processes and strategies that contributed to successful

employment for study participants. Additionally, three key environmental structures shape and

influence the overall process of working successfully. These are the *Work*, *Community*, and

Public Policy Domains. Each of these categories subsumes several

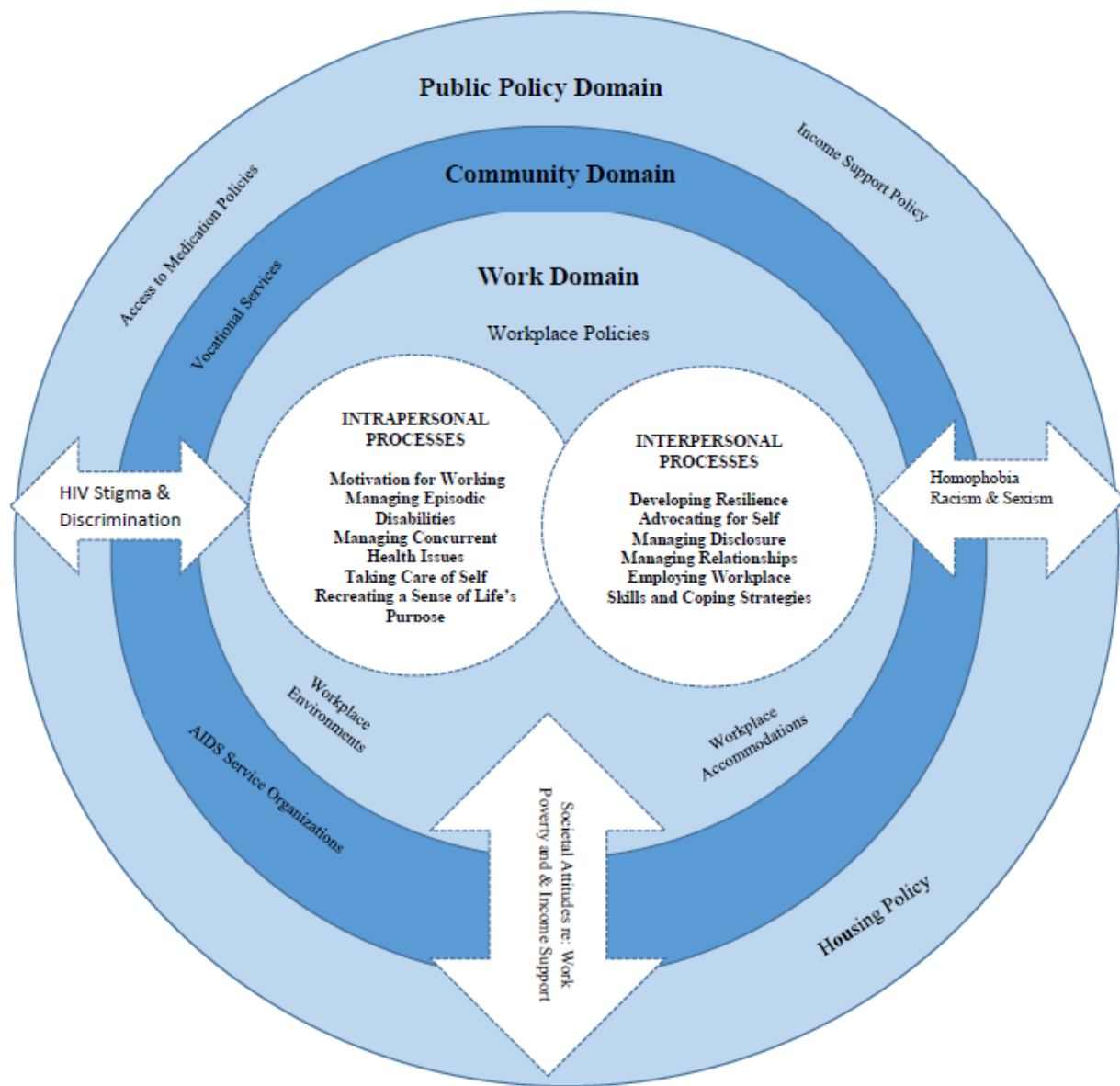**Figure 9.1 Work in Progress: A Conceptual Framework for Understanding the Successful Vocational Experiences of People Living with HIV in Canada**

relevant sub-categories that were discussed in detail as part of the study findings. These

categories are illustrated in a Venn diagram in order to conceptualize them as interacting with

each other in mutually influencing transactions. Additionally, this framework includes one

intersecting subcategory related to culture, power, and social beliefs. This category, entitled *Stigma and Discrimination* is embedded in, surrounds, and influences the processes and structures related to the phenomenon of working successfully. This category is represented in the framework in its three variations: *HIV stigma and Discrimination*, *Societal Attitudes about Work, Poverty and Income Support,* and *Homophobia, Racism and Sexism*.

This conceptual framework synthesizes the study findings and captures the connectedness and relatedness of each of the six categories. The resultant diagram highlights what was described in the research findings – that many participants' vocational development was shaped, in part, by managing and creating positive transactions with a variety of institutions and structures in the social environment. This further suggests that vocational success, for many study participants, could be located in the interface between personal agency, mediating structures at the community level, and environmental barriers and facilitators. This conceptualization allows for the notion of equifinality. Drawing from systems theory and integrated into the ecological perspective, this concept refers to the notion that, a similar goal can be achieved, "from different initial conditions and through different pathways" (Connolly & Harms, 2012, p.59). Correspondingly, for study participants, there was no universal experience or single pathway to vocational success. Rather they each brought a unique set of personal skills and talents and they each interacted with a diverse range of structures and influences in the social environment.

9.2.1 Intrapersonal and Interpersonal Processes

More specifically, the following conceptual understanding was constructed of the research findings. A variety of factors at the institutional and public policy level both challenged and facilitated personal vocational development. For instance, participants reported encountering

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both barriers and facilitators within workplace environments and among the income support policies governing their access to social and health benefits. As part of working successfully, study participants engaged in a range of intrapersonal and interpersonal processes that required them to marshal a variety of strengths and abilities in addressing these varied influences. For many, working successfully involved some degree of risk taking, pursuing opportunities, and engaging with supportive community structures and resources. Thus, part of working successfully involved adaptation to the social environment. In ecological models, adaptation implies a series of strategies that are meant to effect personal and environmental changes in order to create more positive transactions between the individual and their vocational environment (Saleebey, 2001). Therefore, adaptation can involve affecting both personal changes and change at the environmental level. Interpersonal processes and strategies such as advocating for self, managing disclosure, and challenging stigma were all examples described by study participants as adaptation strategies that both challenged existing structures and affected personal change and growth. To a certain extent, these processes at the intrapersonal and interpersonal level involved a varying degree of personal mastery on the part of participants, a conscious development of strategies and coping mechanisms to deal with complex challenges (Saleebey, 2001). In this study, many participants articulated a deep interest in personal growth and change, which influenced their vocational development. Notable personal level factors that motivated this sense of adaptation included being passionate about work, recreating a sense of life's purpose, and developing resilience. Hence, participants' vocational development involved the mastery of increasingly complex and demanding tasks and environments.

9.2.2 Community as Mediating Structures

In ecological models, agency is distinguished as the ability to develop the resources and knowledge to live well despite challenges; in short, the capacity to make things happen (Saleebey, 2001). A developing sense of personal agency frequently existed among study participants and was created in connection with others and through participating in community life. Indeed the concepts of community and participation figured largely in participants' vocational experiences. An ecological perspective recognizes that many individuals seek a variety of benefits through relational communities, including connectedness, support, and a sense of meaning (Maton, 2000). Many study participants described a range of community resources which they connected with in order to facilitate vocational success. Engaging with AIDS service organizations and vocational services on a variety of levels was identified as potentially ameliorating the effects of environmental barriers and assisting individuals to enjoy a fuller sense of social participation. In general, these services were designed to provide increased resources and supports in managing vocational transitions and addressing environmental barriers. Thus, for many participants, success was due in part to their involvement in community structures; experiences that often assisted them in developing agency and learning more about themselves. Consequently, work was seen by many as an activity that not only provided an income but also brought them into a closer connection with other people and their communities.

9.2.3 Environmental Factors

A specific focus on environmental factors and public policies shaping vocational trajectories is an important focus of this framework and a gap in much of the HIV and employment literature. A focus on environmental factors distinguishes ecological models where such determinants are seen to influence individual behaviour (Sallis et al., 2008). Ecological

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perspectives stress the need for analysis and advocacy at the public policy level to ensure that all groups in society can gain access to needed resources (Maton, 2000). According to study participants, applicable social and public policies governing HIV and employment provided a measure of flexibility allowing many to attempt work. However these policies often ensnared individuals aspiring to create increased financial self-sufficiency and independence for themselves through work. A lack of integration between income support policies, access to medication policies, and housing policy often created complex barriers that hampered participants' vocational success. Much of the vocational research, theory, and practice literature reflects what Warnath (1975) terms, "romantic individualism" (p.475). That is, it assumes labour market equity and stresses personal agency rather than environmental barriers (Warnath, 1975). This supposition proves problematic when conceptualizing work for those from marginal social locations, as is the case with the present study. Traditionally, opportunity for vocational success has been limited to those from select groups who historically have had greater access to resources in the social environment. Thus, vocational activities tend to be structured within an inequitable distribution of wealth, power, and resources (Bluestein, 2006; Borgen, 2005; Richardson, 1993).

9.2.4 Stigma and Discrimination

Despite strong determination and a sense of agency, environmental and social factors imposed a variety of restrictions on many study participants. Oppression, stigma, and discrimination are all elements in ecological models that compromise an individual's capacity to adapt, rebound, and achieve success in life and work (Saleebey, 2001). Several study participants identified HIV stigma, societal attitudes about work, poverty and income support, and homophobia, racism and sexism, as factors that were embedded throughout their vocational

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experiences. Thus this conceptual framework also considers issues of power and privilege when conceptualizing participants' vocational transactions.

9.3 Theoretical Implications

Having broadly summarized the Work in Progress Framework, including a brief discussion of each ecological domain; the following section will further situate key findings of the study and discuss their theoretical implications. Additionally, this section will provide a more extensive discussion of the framework and its contribution to the knowledge base in relation to the established literature on HIV and employment. This section is organized into relevant themes that emphasize the connections between each of the ecological domains identified in the framework. These themes include ecological models of HIV and employment; occupational identity; strengths and resilience; workplace environments; community and participation; and diversity and vulnerability. Areas of contribution to the current theoretical and empirical literature on HIV and employment, vocational service provision, and social work practice will be highlighted.

9.3.1 Ecological Models of HIV and Employment

The project of conceptualizing HIV and employment is a relatively new one, and much of the early work in this discipline comes from a counselling psychology perspective. Historically, these efforts tended to draw on theories of career development that focus on individual level constructs such as career development and self-efficacy. As discussed, the basic assumptions of this perspective are individualism, linear career development processes, and equal opportunity (Barrio & Shoffner, 2005). Unfortunately, these suppositions are contradicted by data that suggest that the diversity of populations affected by the disease and the dynamic nature of career

development diminish the degree to which these theories can effectively be applied to people living with HIV. Subsequently, several authors have argued for the need to view employment in a broader context and from diverse social locations such as race, class, gender, ability, and sexual orientation (Bluestein, 2006; Borgen, 2005; Richardson, 1993).

In contrast, The Work in Progress conceptual framework contributes to a growing body of research that conceptualizes HIV and employment within broader perspectives. Responding to the need for vocational theory that addresses environmental constructs, emerging research has begun to more fully address the social and cultural factors that often impose restrictions on persons with a health condition such as HIV. Thus, these approaches contribute to theory and practice by shifting the focus from psychological perspectives that prioritize personal level factors towards a consideration of the dynamic interaction with the environment that shapes and influences the nature of work in people's lives (Szymanski & Hanley-Maxwell, 1996).

The current framework builds upon earlier qualitative research in Canada and the United States that has begun to respond to the need for a more contextualised approach to HIV and employment. Rather than adapt existing vocational theories to the HIV population, these approaches utilized inductive methodologies in order to generate emergent theory that closely fit the diverse vocational experiences of people living with HIV. The current framework extends this tradition and supplements specific contributions made by several recent studies arguing for an ecological approach to HIV and employment. Having already been summarized and explained in Chapter Two these studies will be briefly identified in order to better contextualize the current findings and to illustrate the emerging importance of ecological models in vocational theory for people living with HIV.

First, Ferrier and Lavis (2003) used grounded theory methods in developing the *Considering Return to Work Model*. As discussed earlier, this model identified the factors influencing return to work for people living with HIV and identified income support policies and workplace factors as influential contextual factors in Canadian jurisdictions. This model also acknowledged that earlier studies conceptualizing return to work were focused on personal decision making processes and often failed to recognize environmental constructs in their models. Secondly, Conyers (2004) used grounded theory to develop an ecological model addressing career development for people living with HIV. In addition to individual level constructs, she identified contextual and environmental factors as relevant, including workplace environments and cultural beliefs. As part of this discussion, she suggested that cultural beliefs should be a priority when considering career development for people living with HIV. Subsequently, Maguire, McNally and colleagues (2008) developed an integrative model for understanding the employment needs of people living with HIV. This model shifted understanding of the terrain as it featured a large sample of over 100 people living with HIV and was one of the first qualitative studies that was not focused solely on the return to work process. The research team identified contextual factors as salient within the health, employment, and community domains. Finally, Worthington et al. (2012) conducted a scoping study on HIV and employment, which led to the development of the HIV and employment framework that consolidated the literature on HIV and employment to that point. The framework incorporated six key components related to labour force participation for people living with HIV: the meaning of work, characteristics of work, contextual factors that influence employment, barriers and facilitators to employment (issues related to the personal, employment and public policy domains), strategies and supports for entering, returning to and/or sustaining employment and

potential outcomes of labour force participation (risks/benefits for individuals, and costs/benefits for employers, governments, and insurers). It also identified several conceptual gaps and areas where evidence is lacking, notably in areas related to public policy and contextual factors.

The Work in Progress Framework expands upon these earlier ecological models in recognizing the uniqueness of each individual's transactions with his or her environment. Additionally, the framework highlights several contextual domains where gaps have traditionally existed including at the institutional, community, and public policy levels. The diverse perspectives of people living with HIV from a variety of social locations are integrated in the findings, many of which have traditionally been missing from vocational research and theory. As such, the strength of this conceptual framework lies in a holistic approach to the issue of HIV and employment, and an ability to incorporate diversity and complexity.

An additional strength of ecological models are their ability to incorporate and complement other theoretical approaches. The ecological framework generated from data in this study is consistent with a social model of disability in that it locates disability within the social and cultural barriers that individuals encounter in their environments. Emergent data further support contentions in the literature that, under certain conditions, people living with HIV are often able to manage episodes of illness and successfully remain in the labour force for considerable periods of time. Additionally, the framework is consistent with the World Health Organization's International Classification of Function, Disability and Health in promoting an ecological understanding of disability as a dynamic interaction between health conditions and contextual factors (Hwang & Nochajski, 2003). As such, this work responds to the call for increased focus in the HIV and employment literature on the interaction of individuals with environmental barriers.

Additionally, this study endeavoured to take a divergent approach in utilizing a strengths perspective to conceptualize vocational success. A strengths perspective involves viewing individuals and communities in relation to their capacities and competencies, as well as recognizing the knowledge and resources they possess (Saleeby, 1996). Consistent with an ecological approach, the strengths perspective recognizes that there is reciprocity between individuals and their social environments. Rather than only conceptualize the problems related to HIV and employment, these findings focus on the factors that support individuals in achieving their vocational goals and identifies the strengths and environmental resources necessary to assist them. Thus, given that specific vocational barriers and challenges had been clearly identified in previous research, the main focus of this study was to identify factors that contribute to participants' success in meeting these challenges and achieving their vocational goals. As such, the research findings are structured within a strengths perspective and endeavour to chart participants' diverse pathways to vocational success. This constitutes a novel contribution to the theoretical literature on HIV and employment, which has tended to focus on barriers, needs and deficits.

9.3.2 Occupational Identity

Findings from this research add to a body of literature suggesting that identity construction is an important factor in understanding the successful employment trajectories of people living with HIV. The HIV and employment literature suggests that the concept of work intersects with processes of identity construction. For many people living with HIV, recent histories with illness and unemployment have led to a corresponding loss of purpose and life meaning. Braveman and Helfrich (2001) define occupational identity, "a sense of who one is and wishes to become as an occupational being", as an important intrapersonal process involved in

vocational development (p.119). Additionally, several authors have suggested that for some people living with HIV, transitions related to labour force participation might include the need to create or recreate a sense of identity in a new vocational role (Dickson-Gomez et al., 2004; Goldstein et al., 2004). Occupational identity requires a high degree of self-knowledge and involves building upon personal capacities and experiences in developing a "value based vision of who one wants to become" (Braveman & Helfrich, 2001, p. 25). Thus the concept of occupational identity has been theorized as a strong influence in the success of people living with HIV who were returning to work.

For many participants in this study, work was reported as a means to constructing a new occupational identity and creating a sense of purpose in their lives. Study findings further suggest that identity construction was an important factor in understanding the successful employment trajectories of people living with HIV and contributes a broader understanding of this phenomenon. This study expands on earlier research on HIV and occupational identity in providing rich description of these processes and their importance to many participants. Work was described by many study participants as an important process through which they could reinvent themselves in a new vocational role. Recall that many study participants offered narratives suggesting that work was an activity that facilitated a variety of meaning making processes including connecting with a passion, recreating a sense of life's purpose, and reinventing self. Despite the diversity within the sample, many participants described work as an activity that assisted them in learning, growing, and establishing a sense of meaning. Some study participants described their entire sense of well-being as being affected by HIV: including physical, social and emotional impacts. For many, work was seen as an important means to reversing the social, financial and emotional losses they attributed to HIV.

The idea that many individuals aspire to obtain employment that is psychologically and emotionally rewarding and that provides possibilities for career advancement was also corroborated in this study. For many study participants, the idea of reinventing self was closely linked to work and occupational identity. Several individuals described changing careers and jobs as part of vocational development. Not content to continue in a past vocational role, many were constructing new occupational identities and transitioning to new forms of work. For some this meant jobs they found meaningful and that better incorporated the experience and knowledge they brought as people living with HIV. A desire to connect socially with other people and to contribute to the community have been identified as important factors in the HIV and employment literature (Brooks & Klosinski, 1999). This was also the case among study participants, several of whom sought out employment in AIDS service organizations and other health and social service providers as part of creating new vocational identities.

Ecological approaches to identity construction stress the importance of seeing this process as embedded in relationships and connected to the surrounding culture (Saleebey, 2001). Study participants described how their occupational identities were influenced by prevailing cultural assumptions related to work. Echoing Nixon and Renwick's (2003) assertion that occupational identity is constructed in part within community expectations, norms, and structures, study participants described drawing from cultural symbols in constructing meaning and identity in the context of work. In this respect, the idea of not working was challenging to many participants who described staying at home as "lazy" and a failure to contribute to society. Many judged other community members who looked well but were not working. Thus, prevailing societal attitudes regarding poverty and income support were internalized by many

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study participants, impacted their self-concept, and partly motivated their participation in the labour force.

Despite differential access to resources and a variety of vocational barriers, all participants were engaged in a process that involved defining who they wanted to be as people and what they really wanted to do with their lives post diagnosis. Certainly some participants described barriers to creating a satisfying occupational identity. A range of factors including sexism, racism, and restrictive public policy meant that some hadn't actualized these goals. Several female participants, particularly sole support parents, described sacrificing their vocational development for caregiver responsibilities within the home. Additionally, many immigrants encountered systemic barriers that prevented them from developing their vocational goals. Nevertheless many expressed determination and hope that they would find a way to move forward in creating a new occupational identity that fully expressed their aspirations.

9.3.3 Strengths and Resilience

Resilience has been conceptualized within a number of disciplines. Within the social work literature, resilience is understood as the ability of individuals to rebound under difficult circumstances as well as the capacity to construct a satisfying and productive life in the face of obstacles (Saleebey, 2001). Rather than simply a personal capacity, contemporary understandings position resilience as a relational dynamic; a response to a variety of biological, social, and environmental threats (Fraser, 1999). Thus, it is an interpersonal construct involving successful adaptation to negative life events such as illness, trauma, stress, and significant change (Emlet et al., 2010). In an HIV context, resilience has been defined as, "the capacity of individuals and groups to move forward with hope, clarity, and effectiveness in the face of multiple losses, complex grief, and ongoing transition related to HIV/AIDS" (Perreault, n.d.) .

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Regardless of the disciplinary lens, all definitions of resilience involve the core processes of confronting, gradually adapting, and integrating an adverse event into one's life (De Santis, 2008).

Resilience is a concept that is readily conceptualized within an ecological perspective as evidence suggests that it involves both individual capacities and the social context (Fraser, 1999). As such, resilience can be discovered not just in individual competencies but in how these interact with social environments and contextual factors (Rutter, 1993). Research has suggested that there is a high degree of variability in how people react to adversity, with the number of people responding with resilience being relatively small (Fraser, 1999; Rutter, 1993). Contemporary authors suggest that a continuum exists between resilience and vulnerability and that those with high levels of personal and social resources are often more effective when confronted with life stressors (Moen & Erickson, 1995). Here, vulnerability is seen as any experience that creates stress, anxiety and physiological, psychological or social distress (De Santis, 2008). Thus, in the context of HIV and employment, resilience is an extremely important concept since, as Fraser (1999) suggests, "the promise of resilience is to learn from success." (p. 136).

To date, very few studies have discussed the idea of resilience in relation to chronic disease or HIV (Emlet et al., 2010). A systematic review, conducted in 2008, identified only seven papers addressing resilience in the context of HIV infection (De Santis, 2008). In some Canadian studies, resilience has been established as an important factor in the context of HIV related multiple loss (Perreault, 1995, 2007). In other studies, people living with HIV have been characterized as both resilient and vulnerable depending on the course of HIV infection; establishing that different degrees of vulnerability and resilience probably exist within this

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population (De Santis, 2008). Common vulnerabilities identified in the research on HIV and resiliency include age, ethnic minority group status, primary language other than English, having young children, disabled or unemployed status, receiving public assistance, a history of drug or alcohol use, a history of crime, and history of commercial sex work (De Santis, 2008).

To date, the concept of resilience has rarely been explored in the HIV and employment literature. Thompson (2003) has suggested that people living with HIV engage in work to lessen their financial vulnerability and increase resilience. Additionally, Maguire (2008) recognized physical and emotional resiliency as adaptive responses among people living with HIV who struggle with employment and work issues. Otherwise, scant attention has been given to the concept of resilience in the HIV and employment literature. The following discussion builds upon the latter two studies in suggesting that resilience is an important construct in the context of HIV and labour force participation.

Resilience as an adaptive response to the challenges of HIV and employment was a concept that emerged from the data in this study and contributes to an emerging focus on strengths and resilience within the HIV and employment literature. At different times throughout vocational transitions, participants reported a continuum of responses that ranged from vulnerability to resilience. Despite the diversity of responses, the findings support two main ideas. First, successful employment appeared to be a product of participants' resilience. Secondly, working tended to support the development of resilience among many study participants. Thus, a mutually reinforcing relationship between work and resilience helped many participants to counter the effects that the disease had over their lives.

Successful adaptation is a core concept in resilience and an important component of ecological perspectives. Several authors from both disciplines have identified adaptation as an

important capacity within resilient responses (Rutter, 1993; Saleebey, 2001). In the context of HIV, a resilient response has been characterized as the ability to utilize a repertoire of strategies in successfully adapting to the diagnosis and integrating the illness into one's life (Cadell, Karabanow, & Sanchez, 2001; De Santis, 2008; Emlet et al., 2010). As described in the findings, a resilient response in the context of the multiple challenges related to HIV and employment was characterized by a variety of strategies. Specifically, participants described recovering from illness and loss, actively pursuing their vocational goals, learning from earlier experiences, and drawing upon support from family and friends. By this measure, it seems clear that in order to work many study participants have had to successfully adapt to the illness and integrate the disease into their life.

The idea that occupational success improves coping, increases access to social and economic resources, and enhances resilience has been proposed in the both the HIV and employment research and in the theoretical literature (Moen & Erickson, 1995). Participants in this study corroborated these findings, attributing an increased sense of resilience to their ongoing participation in the labour force. For some, work was a key protective factor reinforcing their role as active agents in their own survival and growth and providing opportunities for increased social status and quality of life. As described in the study findings, many participants attributed improved emotional, physical and financial health to their participation in the labour force and described a decreased sense of social isolation.

As with many other concepts in this framework, resilience was interrelated with several other subcategories and occurred within several domains. Thus, in addition to existing as a distinct subcategory and interpersonal process, resilience is a concept that was implicated as an underlying factor in several other categories. In particular, there were several close connections

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with intrapersonal processes, and strategies enacted by participants within the interpersonal and community domains.

A range of personal capacities are identified in the literature as supporting resilience. For instance, Rutter (1993) identified competencies in coping and problem solving as key properties related to individual resilience. Thompson (2003) further suggests that successfully coping with illness is a key factor supporting resilience in the context of HIV. Findings from this study suggest that a range of general coping strategies and competencies employed by participants contributed to their success in the workplace. Managing episodic illness, employing workplace skills and coping strategies, managing disclosure, and advocating for self were additional processes identified by study participants that reflected a growing sense of resilience in the face of the challenges associated with HIV and employment.

Being determined and planning for the future were intrapersonal processes that supported adaptation and were important components of a resilient response. Within an ecological perspective, optimism, and a belief in the future are core convictions that help to sustain people as they confront difficult situations (Saleebey, 2001). Furthermore, planning for the future despite a serious illness, and tolerating the uncertainty associated with HIV are seen as key measures of resilience in the context of HIV (Emlet et al., 2010; Thompson, 2003). Study participants demonstrated that, given the health and social challenges related to living with HIV, optimism can be difficult to sustain. Responses ranged from fear and worry to more resilient approaches such as actively strategizing for the future. Regardless, most participants were actively engaged in a process of contemplating their future. This future orientation underscored a resilient response and engaged participants in a range of strategies they were utilizing as part of realizing their career ambitions.

In general, a majority of participant narratives were distinguished by a strong motivation and determination to work regardless of their past experiences and challenges in the workforce. This was an important element that inspired a resilient response and contributed towards vocational success. Although a variety of research studies have documented that a high proportion of people living with HIV in North America would like to be engaged in the workforce (Brooks et al., 2004; Fesko, 2001; Jalbert, 1997), other studies have documented a degree of ambivalence and uncertainty regarding employment (Ferrier & Lavis, 2003; Maguire et al., 2008; Nixon & Renwick, 2003). This is most likely due to a number of occupational barriers and the well documented risks associated with returning to work for people living with HIV. Findings from the current study offer a more complete picture of the high level of motivation required to successfully navigate working and living with HIV, and posits the determination to work as an essential factor.

This connection between resilience and a determination to work resonates with other work conducted in this area. Many of the motivations to work discussed by study participants have been documented in earlier research. For instance, the connection between improved health and increased motivation to work as well as the need to create a sense of independence and financial self-sufficiency through work has been established by several authors in the post HAART literature on HIV and employment (Brooks et al., 2004; Conyers, 2004a; Ferrier & Lavis, 2003; McReynolds & Garkse, 2001). Nevertheless, a high level of personal determination and a passion for work stood out as distinct personal qualities common to many participants. In contrast to the ambivalence found in earlier research, study participants credited their success in the labour force to a passion for their job, and a simple love for the work they do. In some cases, this determination was described as the, "fire within" (participants 6, 3,7); an inner source of

motivation that kept participants reaching farther. Many indicated that staying at home was simply not an option they would consider in the long term. Even those who found themselves in difficult workplace environments expressed a determination to locate work they felt better connected to. Many also recalled negative experiences in earlier jobs; situations that they eventually left. Clearly, many participants had located work that aligned with their personal values and vocational goals. For many participants, this sense of vocational "fit" coupled with a supportive workplace environment led to a resilient response.

9.3.4 Workplace Environments

An important consideration that has not been adequately addressed in the HIV and employment literature surrounds the question: what aspect of workplace environments contribute to successful employment? Due to its focus on people living with HIV who are successfully working, this study is in a unique position to contribute to conceptualizing supportive workplaces. Unfortunately, to date, very little research has been published on the factors that contribute to supportive workplace environments and that may help facilitate successful employment for people living with HIV. Studies addressing workplace environments often predate the introduction of effective medication to treat the illness and address the U.S. context, meaning that they are less relevant to the present Canadian context. Nevertheless, appropriate workplace accommodations, supportive policies, and explicit initiatives to reduce discrimination have all been identified as contributing to improved work environments for people living with HIV (Conyers & Boomer, 2005; Ferrier & Lavis, 2003).

These findings were further corroborated in this study. A number of participants characterized their employer as being generally supportive and that working in a supportive workplace environment was seen as essential. Building upon previous findings from the

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literature, several individuals attributed their success to working in an affirmative and accommodating work environment that recognized their contributions and provided effective management. Here relationships were seen as important factors. Several participants described the importance of a trusting relationship with the employer where their contributions were recognized in creating a supportive work place. In this regard, the role of the manager was described as significant. Many participants regarded their co-workers with fear and some concealed the disease in order to protect against hostility and stigma. In this context, supportive managers often set the tone for organizational responses to HIV in the workplace and were instrumental in creating positive and supportive workplace environments for some participants. Several participants described supportive managers as pivotal in gaining recognition, securing accommodation, and successfully sustaining employment. Within supportive workplaces, many participants described environments in which they could learn and grow, share their experiences as people living with HIV, and gain support from their peers.

Also corroborating earlier findings, study participants identified workplace accommodations as an additional factor structuring supportive workplaces. Participants identified three main areas for accommodation: flexible or modified schedules, facilitated adjustment to the workplace, and a change in work duties or responsibilities. While all these factors have been identified in earlier research, the current findings highlight the role of flexible work schedules in successful employment. Whether as an employer provided accommodation, or as part of a preference for part time positions; flexibility of hours was reported as critical by many study participants. A majority of participants who discussed accommodation reported requiring a flexible schedule in order to manage their illness effectively. Additionally, several indicated a preference for slightly less than a 40hr work week in order to maintain emotional

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balance and self-care. Earlier research has documented employer concerns regarding the potential costs of accommodation as well as an inability and unwillingness to accommodate people living with HIV in the workplace (Hergenrather et al., 2004; Hunt et al., 2003). However, results from this study counter those concerns and confirm that many people living with HIV can be successfully accommodated with minimal or no cost to the employer. In all cases, participants described requesting flexible hours as opposed to decreased hours, a standard accommodation that had minimal impact on the employer and that could be considered cost effective given the experience and skills that many participants contributed in their workplaces.

9.3.5 Community and Participation

The concepts of community and social participation resonated strongly with study participants, many of whom expressed a desire to connect with and contribute to the broader community and participate fully in society. Within ecological perspectives, community is understood as a major source through which political and social forces exert influence on individuals' lives and as, "mediating structures that serve as connections between individuals and the larger social environment" (McLeroy et al., 1988, p. 364). In an HIV context, the benefits of relational community can be realized through self-help groups, voluntary associations, and community service agencies such as AIDS service organizations. The benefits of participation in these groups have been theorized to include increased social connectedness, support, safety, shared values, and enhanced meaning (Maton, 2000). Participants in this study reported engaging with AIDS service organizations in a variety of ways, including accessing services, connecting with peers, participating in leadership training, volunteering, and through paid employment. Consequently, for many participants, AIDS service organizations helped participants deal with

environmental barriers, facilitated increased community involvement, and served as a pathway to successful employment.

The importance of community participation in the context of HIV and employment has only minimally been recognized in the theoretical literature and as such these findings form a useful contribution. Bluestein (2006) has suggested that the importance of work lies in its ability to not only provide a living but in its capacity to bring one into closer connection with other people and their chosen communities. Nevertheless, the role of community in the HIV and employment literature is rarely considered beyond the need for social service provision. For example, the responsibility for community agencies and AIDS service organizations to provide needed supports to people living with HIV is well recognized. Also, access to community resources such as counselling and practical support services have been acknowledged as useful supports for those individuals living with HIV who are considering work (Hyduk & Kustowski, 2003). Additionally, care giving, community involvement and volunteering have long been recognized as vocational alternatives to work for people living with HIV (Blustein et al., 2008; Hunt et al., 2003). Nonetheless, the capacity of AIDS service organizations and other community groups to facilitate community participation has been overlooked in the literature on HIV and employment and it has remained unclear what role, if any, these organizations play in providing a pathway to successful employment for people living with HIV.

Findings from this study suggest an enhanced role for AIDS service organizations as potential community structures that can facilitate increased social participation, better connect people living with HIV with their communities, and assist them in developing the skills and capacities for successful employment. Certainly, their role as social service providers was not underestimated. Study participants frequently described practical assistance and food security

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programs as support services delivered by AIDS service organizations that were instrumental in assisting them to maintain successful employment. These supports were seen as indirectly supporting their vocational development by helping them meet needs that they could not adequately meet solely with income from employment. Peer support programs were also a valued part of service provision within AIDS service organizations in the few cases where they existed. Many participants wanted to connect and gain support from other people living with HIV who were experiencing similar challenges and saw AIDS service organizations as an important venue in which this could occur.

Nonetheless, study findings also established AIDS service organizations as more than just providing needed social services. Working from an empowerment model, some AIDS service organizations reportedly supplemented service provision with leadership training and capacity building programs for people living with HIV. Many study participants described these initiatives as important bridges to fuller participation in the community AIDS movement and subsequent employment. Many individuals reported confronting power inequities, stigma and discrimination, and restrictive public policy in charting a course to successful employment. Involvement in AIDS service organizations and other community agencies better equipped some participants in managing these loaded interactions by offering supportive environments and providing opportunities for personal and community empowerment. While not explicitly developed as vocational interventions; leadership development programs delivered by regional and provincial AIDS service organizations assisted many participants in developing the skills and capacities to be successful in employment.

Additionally, almost half of study participants reported volunteering in the community and within local or provincial AIDS service organizations. Volunteering reportedly provided

meaningful experiences for many study participants and fulfilled a desire to contribute to the

community. For these participants, volunteering was a manageable route to explore their

employment options and several described developing skills that assisted them in securing

sustainable employment. In many cases, these volunteer experiences helped provide a sense of

connection, and directly supported participants' route towards employment. Many of these

participants reported working in AIDS service organizations as an extension of their community

and volunteer involvement. The success of AIDS service organizations in facilitating community

participation contradicts other accounts published in the recent literature. Several community-

based studies have documented systemic shifts within Canadian AIDS service organizations

since their inception in the 1980's. These changes highlight the difficult challenges facing these

relatively young organizations as they develop in response to the rapidly changing AIDS

pandemic. These developments include a shift from activism to service provision and the

ongoing bureaucratization of the sector (Cain, 2002; Collins et al., 2007). The result has been

instability within some agencies and the alienation of many groups of people living with

HIV/AIDS (Collins et al., 2007). Consequently, AIDS service organizations increasingly tend to

engage a smaller cross section of people living with HIV within their governance. For example

in the province of Ontario, research suggests that 33.3% of ASOs organizations have no self-

declared HIV positive staff and that the majority have less than 50% representation of people

living with HIV on their Boards (Collins et al., 2007). This evidence suggests caution in

idealizing or simplifying the community engagement role of AIDS service organizations.

Certainly, participant narratives reflected some of the tensions identified in the research

literature. Many challenges associated with being a disclosed person living with HIV in an AIDS

service organization were identified, particularly with regard to tokenism and dual roles as

service provider and client. Additionally, several participants discussed encountering racism, sexism, and stigma, as employees and clients of AIDS service organizations. A few discussed the inability of these organizations to meet their service needs and some did not see themselves as requiring services from AIDS service organizations. Additionally, some participants who were working in AIDS service organizations were effectively sacrificing access to benefits and financial stability in order to work in AIDS service organizations and make a valuable contribution to their communities. Nevertheless, the majority of study participants were among the population of people living with HIV who remain closely connected to these organizations and who are engaged in the dialogue and community politics that continue to shape their future.

In addition to being closely engaged with AIDS service organizations, several participants described themselves as advocates for the greater involvement of people living with AIDS principles (GIPA). Discussed earlier, this internationally recognized policy statement commits governments and organizations to the equitable involvement of HIV positive people in all decision making processes that affect their lives (UNAIDS, 1999). The principles are now being integrated into the Canadian AIDS movement and have been endorsed in policy by the Canadian AIDS Society, The Ontario AIDS Network and many of their members (International HIV/AIDS Alliance & The Global Network of People Living with HIV, 2010; Ontario AIDS Network, 2011). As a result, many local AIDs service organizations in Canada have attempted to implement the GIPA principles both in policy and in programming. Although the adoption of the GIPA principles has raised tensions, the success of study participants in engaging as volunteers and employees within AIDS service organizations may perhaps be attributed to an increasing ethic of meaningful participation within the community-based AIDS movement. A high proportion of study participants worked or hoped to find work within AIDS service

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organizations. Many did so because they valued inclusive workplaces where they could participate fully and where they were able to share their experiences as people living with HIV. Rather than existing as beneficiaries of GIPA policies, several participants described taking on a leadership role and advocating for GIPA policies within AIDS service organizations and other employers. The importance of the GIPA principles was recognized by those working in AIDS service organizations; the leadership programs and capacity building efforts developed by networks of AIDS service organizations and valued by many study participants as critical learning experiences reflect an increasing focus on the role of participation and empowerment that is reflected in the GIPA principles. These programs represent a shift for many AIDS service organizations, and were seen by a variety of participants as contributing to community engagement and supporting their vocational development. While certainly less than perfect, AIDS service organizations that incorporated the GIPA principles were regarded by study participants as more supportive employers. Thus, there is a potential that the GIPA principles may serve as a guide for mainstream employers around how they can best accommodate people living with HIV in the workplace.

The concept of community and participation is well integrated within ecological perspectives. For many participants in this study, their pathway to vocational success involved active involvement in the community, and in particular in AIDS service organizations. Many participants described what Saleeby (2001) has termed generativity: "an aspiration to give back to the community through advocacy or acts of service" (p.74). Thus peer programs, leadership training, volunteering, and eventually working in AIDS service organizations facilitated positive interactions with community structures that helped many participants find meaning, develop vocational purpose, and reinvent themselves in new vocational roles. For many, this supported a

developing sense of resilience that was facilitated through reciprocity and community connectedness.

9.3.6 Diversity and Vulnerability

In an ecological perspective, access to social, cultural and economic resources and a position in the larger social structure are key to successful adaptation (McLeroy et al., 1988). In the context of HIV, mobilizing environmental resources to cope with the illness is an important factor in creating quality of life. Generally speaking, opportunity for vocational success and occupational choice has been limited to individuals and groups who have had greater access to resources in the social environment (Warnath, 1975). Consequently, issues of power and privilege must be considered when conceptualizing study participants' vocational transactions.

Despite the vocational success and resilience demonstrated by study participants, the findings from this research indicated that vocational success was socially differentiated according to race, ethnicity, gender, disability, sexual orientation, and/or social class. Specifically, those participants who were women, recent immigrants, from visible minority groups, or who were not in the professional class were more likely to encounter additional barriers related to their social status. Experiences of racism and sexism characterized their transactions with important resources at the institutional and public policy level hampering their vocational success.

Despite the fact that the majority of study participants reported a post-secondary education and a high level of skills, many participants reported working in very vulnerable conditions with inadequate coverage or no benefits of any kind. Thirteen participants, many of whom were engaged in part time, contract, or temporary work reported receiving no paid sick leave entitlement as part of their employment; a critical lack of coverage for vulnerable

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individuals with episodic health conditions. Regrettably, these participants were more likely to be women, immigrants and/or from visible minority groups. As a result, these same participants were also more likely to be part of the working poor and reported depending on supplemental social supports. Despite working and receiving extra income, these participants reported still facing financial vulnerabilities and relying on AIDS service organizations for financial assistance programs and food banks to assist them to make ends meet.

As a group, women participants encountered some specific barriers related to their gender. Although less likely to have been living long-term with HIV, the women in the study were more financially vulnerable and less able to take risks. In comparison, gay men reported being more likely to volunteer within AIDS service organizations, possibly due to less family responsibility. As detailed in the study findings, the women participants carried a greater burden as care givers for children and other family members; responsibilities that combined with HIV to limit their career aspirations. In general, the women participants were more likely to compromise their future career goals for jobs that provided some degree of financial stability for them and their families. This responsibility to their families often included additional financial burdens associated with caring for children, extended family and out of country remittance payments; obligations that demanded considerable resources. In contrast, only one male participant described caregiver and parental responsibilities as a vocational stressor.

Additionally, HIV stigma, sexism and racism combined in creating gender and racial differences related to the ability to publicly disclose HIV status. Women who had children, or family and caregiver responsibilities, reported being less likely to disclose their status at work as they felt responsible for any consequences family members may have faced due to their disclosure. Additionally, recent immigrants and those from ethnic minority populations were

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often concerned about their HIV status being breached within familial and community networks and often feared that this news would reach their country of origin. As discussed in earlier chapters, the resultant efforts to conceal the disease caused many participants high levels of stress and kept them from fully participating in the workplace.

Remaining competitive in the Canadian labour market was a particular issue for immigrants to Canada who described the added burden of acculturating to a new workforce. In addition to facing racism and discrimination, several participants reported language barriers and the failure of Canadian employers to recognize their experience and credentials as workplace barriers. These issues often jeopardised participants' employment trajectories and made it more difficult for them to be successful in the workplace. Despite their training and education, many of these individuals were relegated to positions as labourers and to other low paying jobs. These issues jeopardised participants' employment trajectories regardless of country of origin or length of time in Canada, with women and those from developing countries reporting more difficulties in overcoming these barriers.

These findings substantiate other issues related to gender and race that have begun to be reported in the HIV and employment literature. Bluestein (2006) has suggested that the world of work is often where social inequities and injustice appear most evident. Gender, immigration status, and ethno cultural background have all been increasingly identified as important factors in the HIV and employment literature where a complex interaction between personal, environmental, and health factors have begun to be identified (Burns et al., 2006, 2007; Onwumere, Holttum, & Hirst, 2002; Solomon & Wilkins, 2008). Workplace stigma and discrimination targeting people with disabilities and those living with HIV have been documented in the research literature, establishing HIV stigma, homophobia, racism, and sexism

as specific vocational barriers (Adkins, 2002; Brooks et al., 2004). Several studies in the U.S. and France have established that deeper levels of workplace discrimination are experienced by people living with HIV (Conyers et al., 2005; Dray-Spira et al., 2005). Although limited by the small number of study participants from these particular groups, the current findings offer support to progressing efforts at providing a more diverse understanding of labour force participation for people living with HIV by considering work in a broader context and from some diverse social locations such as race and gender.

9.4 Implications for Public Policy and Vocational Service Development

This dissertation contributes to the HIV and labour force participation literature in Canada. It provides theoretical insight into Canadian environmental factors influencing the employment experiences of people living with HIV and takes an ecological and strengths-based approach to an understudied and pressing social phenomenon. In addition, the study meets a demonstrated need for local, contextual knowledge in order to inform community responses. The conceptual framework has the potential for the following benefits: 1) increasing understanding of the diverse labour force experiences of people living with HIV, 2) informing policy advocacy and development in this area, and 3) guiding vocational service provision to people living with HIV. The following section will discuss the nature of this knowledge with a focus on its contribution to public policy analysis and the development of responsive and effective vocational services for people living with HIV. Recommendations for future public policy development and social work practice arising from the research findings will be discussed where applicable.

9.4.1 Implications for Public Policy

Substantial research has confirmed that dependence on public income supports leaves many people living with HIV to subsist in precarious financial situations, suffering poverty and

low socioeconomic status (Ferrier & Lavis, 2003; Gillies et al., 1996; Grierson et al., 2004; Stapleton & Tweddle, 2008). While public income supports are essential for those who must rely on them, many participants identified that escaping dependence on these programs was a primary motivation to work. Unfortunately, there is very little research that documents the impact of Canadian income support policies on the employment trajectories of people living with HIV. In the HIV and employment literature, public policy is conceptualized as both a barrier and a facilitator to employment for people living with HIV. For instance in one of the few Canadian studies published on this issue, Maticka-Tyndale, Adams and Cohen (2002) concluded that existing workplace and government policies impede labour force participation for people living with HIV who have recovered from serious illness and are now willing to work. Additionally, Ferrier and Lavis (2003) have suggested that flexible disability pension structures would facilitate improved vocational transitions for people living with HIV. More recently, a scoping study conducted in Canada concluded that the availability of transitional benefits, health benefits, automatic reinstatements, and allowable earning amounts created incentives that enabled people living with HIV to overcome the barriers related to labour force participation (Worthington, O'Brien, et al., 2012).

Analysis of the issues related to HIV and employment and income support policies has been conducted by Canadian AIDS service organizations and advocacy groups. Perhaps some of our most detailed understanding of these issues comes from a range of discussion papers prepared by these groups. This body of work has identified a range of critical issues associated with income support policies, access to medication policy, and housing policy. In summary, these studies have established five main themes that are relevant to the current discussion. First, research conducted with income support recipients in Canada have indicated critical problems

related to income claw backs, reporting, and leaving public benefits (Stapleton & Tweddle, 2008). Secondly, interactions between income supports and other programs cause problems for recipients notably in areas of eligibility and rate levels for subsidized housing (Stapleton & Procyk, 2011). Thirdly, most income support programs are designed to support people with permanent disability as opposed to episodic conditions (Stapleton & Procyk, 2010). Fourth, policy fragmentation within the system makes it difficult for people living with HIV and service providers to understand and navigate the complex and contradictory network of programs and policies put in place by governments at the provincial and federal level (Anderson & Brown, 2005; Canadian HIV/AIDS Legal Network, 2005). Finally, Canadian public policy on pharmaceutical drugs over recent years has prioritized the protection of corporate rights over accessibility to the public (Brown, 2001). Additionally, the current Canadian public policy environment is complex and subject to shifts over time. Frequent changes in income support policies, benefit rates, and eligibility criteria in a variety of jurisdictions means that it is a distinct challenge to access up to date research information on the Canadian income support policy context.

Accordingly, findings from this study contribute to current data on employment and income support policy in several Canadian provinces and identify their impact on participants living with HIV and managing work. In general, study participants' experiences with public income support policies and programs played a major role in their ability to work successfully and income supports were described as both facilitators and barriers to successfully working. Additionally, these findings suggest that income support policy, access to medication policy, and housing policy collectively influence the employment trajectories of people living with HIV.

Planned and delivered in isolation from each other, they had a mutual impact on people living with HIV in this study and often interacted in creating complex barriers to employment.

Flexible employment provisions structured within Canadian public income support policies, such as allowable earning amounts, transitional health benefits, and automatic reinstatements were reported to have a facilitative effect on employment for many participants. Individuals reported exploiting these existing flexibilities in order to work while simultaneously receiving partial benefits. Diverse ways of engaging with income support programs were reported. Many participants recalled a history of receiving full benefits, several combined part time or casual employment with partial income support benefits, and a few maintained full time positions while receiving transitional health benefits. There was no question that without access to these flexible options within income support policies a majority of participants in all three provinces would not have risked employment.

Despite these flexibilities, employment barriers associated with public policies were also identified. In pursuing employment, many study participants put at risk income supports that guaranteed a variety of basic needs would be met, including a sustainable income, access to medication, and affordable housing. Unfortunately, responsibility for income support policies, access to medication policies, and housing policy was often divided between a variety of benefit providers and government departments. Fragmentation in the system and lack of coordination among benefits providers created gaps that often trapped participants in a complex and confusing web of public income supports. Inconsistency among eligibility requirements and means testing often meant that losing access to HIV treatment or housing was a potential consequence of increased income through employment.

This fragmentation also inhibited many participants' vocational development and ability to establish independence. This was particularly the case in Ontario where low ceilings on earnings exemptions, the temporary nature of transitional health benefits, and lack of universal access to HIV medication often trapped participants in part time employment and deterred them from moving forward with independent full time work. In this manner, many participants marginally increased their income by combing part time work with partial benefits from public income supports. Those who combined income supports with work often did so to maintain access to stable prescription, vision, and dental coverage. Unfortunately, many got stuck at this point due to the need to maintain access to these benefits, which were frequently not covered by employers. Thus those working part time and remaining dependent on public income support for transitional health benefits were further ahead financially but only marginally so and many were in precarious employment situations that did not allow for meaningful vocational development.

The ability to connect with the health care resources required to deal with HIV is a fundamental need for people living with HIV, most of whom require a combination of HIV medications to maintain their health (Brown, 2001). As discussed in the findings, these medications are extremely expensive and affordable access often depends in part on which province you live in, your level of income, and whether you have access to insurance benefits. Nevertheless, only two articles reviewed for this study addressed unequal access to HIV treatment, and neither discuss the Canadian policy context of this issue (McFarland et al., 2003; Rosolen, 2002). Additionally, research related to HIV and employment in Canada tends to focus on income support policies without addressing the connections to other areas of public policy. In contrast, findings from this study identified the joint impact that several policies had on the employment trajectories of study participants. In this context, several critical issues related to

access to HIV medication were identified by study participants and suggest that universal access to medication is a potential policy lever that could assist people living with HIV to better manage vocational transitions.

Generally, HIV medication was seen as an employment facilitator as all participants had secured access to treatment and it allowed them to feel healthy enough to be in the workplace. Nevertheless, access to affordable treatment was not an indefinite guarantee for all participants, and some struggled with maintaining access. Universal access, "whereby all residents of the relevant jurisdiction are eligible for the catastrophic drug program on uniform terms and conditions that do not place an unreasonable cost burden on individuals" was the policy goal in British Columbia and Alberta (Kort & Ragan, 2008, p. 7). Here, study participants described accessing their HIV treatment for free through a third party outpatient health clinic. Some of the benefits associated with universal access were that it decreased the risk of HIV disclosure in the workplace, minimized fears for those participants who wished to remain private about their illness, and made it less likely that participants would discrimination in the workplace.

This was not the case in Ontario where catastrophic drug coverage was provided through a variety of means tested programs for those participants who didn't have coverage through their employer. Again, lack of integration within this system caused serious problems for a few participants who despite being employed, fell through the cracks, and were unable to access or afford their HIV medication. In each case, these situations emerged while participants were engaged in vocational transitions where they were moving from one treatment provider to another. Unfortunately, it was frequently those participants who were risking full time employment or otherwise attempting to improve their vocational options who reported significant gaps in coverage that jeopardized their treatment. Those participants who remained

on ODSP rather than risking other forms of employment reported the least amount of difficulties accessing medication.

In summary, several important themes related to public policy emerged from the study findings. Notably, those participants who risked vocational transitions often encountered gaps within a fragmented social policy framework. These gaps meant that, by working, participants risked losing access to income supports, access to treatment, and affordable housing. While many participants were able to successfully negotiate their way through these issues, success did not come without personal cost and financial losses. Policy fragmentation also meant that those with episodic illness may potentially cycle in and out of the workplace, thus risking these transitions multiple times, and suffering instability. Additionally, several Ontario participants reported sacrificing their vocational goals in the interest of maintaining stable and reliable access to free HIV treatment.This was in contrast to participants in British Columbia and Alberta where initiating a vocational transition carried no risk of losing access to treatment. These findings corroborate conclusions from other studies and suggest that maintaining access to medication is closely connected to employment processes for people living with HIV.

Study findings related to employment and public policy inform three main recommendations for advocates, policy makers, and those working in community-based AIDS service organizations. The first recommendation regards automatic reinstatements for income support recipients. Several jurisdictions covered in the study had no explicit policy regarding automatic reinstatements. However if automatic reinstatement to an existing level of benefits were enshrined within in all public income supports it would reduce the risk related to vocational transitions and provide further motivation for people to consider employment. Secondly, universal access to HIV treatment should serve as the guiding principle in a pan Canadian

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approach to catastrophic drug coverage. Providing free HIV medication to those individuals

requiring it, independent of their income supports, and regardless of employment status, would

be consistent with other forms of Canadian health care delivery, and would enable people living

with HIV to more freely pursue their vocational development goals. Finally, working to establish

and communicate consistent eligibility criteria and providing income exemptions for some forms

of social benefits, such as housing subsidies and CPP income, would help ensure that a modest

level of income from employment does not create undue instability for income support

recipients.

9.4.2 Implications for Vocational Service Development

Contributing relevant knowledge that can assist with vocational service development was

a core component of this community-based research initiative. As part of study interviews,

participants discussed their vocational service needs as well as their experiences with HIV

specific and mainstream vocational service providers. These discussions established vocational

services as important mediating structures within the community domain and a valuable resource

to those pursuing vocational goals. Unfortunately, there is only one known vocational service for

people living with HIV in Canada and very few individuals outside of Toronto have access to

vocational service providers who are knowledgeable in the area of HIV. Thus this study adds to a

growing body of literature that can inform the development of effective vocational programs for

people living with HIV in Canada. In this section, participants' perspectives on vocational

service provision will be briefly synthesized in order to inform best practice for AIDS service

organizations and social workers.

Vocational development has been defined in the counselling psychology literature as the,

"academic and nonacademic skills, knowledge, interests, choices, and behaviours that are

acquired before, during and after entry into the workplace" (Bluestein, 2006, p. 11). While useful when working on an individual level, this approach fails to adequately consider the social structural context when providing services to those with serious health conditions who are currently working (Borges, McNally, Maguire, Werth, & Britton, 2008). A need to go beyond individual level analysis is important when working with groups who have a history being discriminated against in employment situations. Expanding on this approach, an ecological perspective provides a holistic framework from which to consider effective vocational interventions at a variety of levels. This study adds to the growing body of evidence suggesting that personal level interventions such as skills building and counselling can assist people living with HIV to successfully participate in the labour force. It also fills a gap in articulating the importance of public policy advocacy and interventions aimed at the environmental level and in assuring that workplace environments are supportive of people living with HIV.

9.4.2.1 A Framework to Inform Vocational Service Development

Study participants described accessing a variety of vocational supports as part of their vocational experiences. These included HIV specific vocational services, mainstream vocational programs, support groups, and peer based models. Additionally, they described other supportive factors as well as gaps in service provision. Based on these discussions, the following nine factors, identified as supporting vocational development, should be considered in the planning and development of effective vocational programs and services for those living with HIV in Canada:

1. **Social and Emotional Support:** Many participants described the difficult emotional and psychological challenges they faced as part of vocational transitions**.** Ongoing social and emotional support by an engaged vocational service professional during and following

vocational transitions was identified by many participants as effective in supporting their employment trajectories. Given the study findings and their focus on the concept of occupational identity the goal of vocational rehabilitation for people living with HIV must be more than simple job placement. Interventions should consider the emotional impact of loss described by study participants and assist people living with HIV to help restore meaning and purpose as part of vocational transitions.

2. **Skill Development**: Study participants discussed the usefulness of skill development supports such as resume writing and interview skill development. Vocational skill development and support for job search as well as long term support for career development and career planning were seen by participants as a necessary component of vocational services.

3. **Benefits Counselling:** Many study participants described struggling to navigate and access the income support, housing and medication services system**.** Gaining an informed understanding of the impact that a change in employment would have on their access to public income supports and other essential benefits was identified as a priority for many study participants. Benefits counselling that addressed issues with public and private benefits providers was described as a valuable component to vocational services provision.

4. **Anti-Oppressive Practice Approach:** Participants described the discrimination and stigma they experienced and feared within the workplace. Given the historical stigma associated with HIV, an explicit focus to assist newcomers, women, gay men and others with the specific barriers they face in relation to stigma and discrimination is a necessary component of vocational service provision.

5. **Peer Support and Mentorship:** Many study participants identified being able to speak with another person who had experienced similar struggles as extremely helpful. Peer support and mentorship that allowed people living with HIV to learn from each other's experiences were a vocational service need discussed by study participants.

6. **Support Groups:** Study findings indicated that many people living with HIV value services above and beyond one to one approaches. Support groups were valued by some participants as an alternative to individual and case management approaches.

7. **GIPA Principles:** a genuine emphasis on the GIPA principles within vocational service provision would help empower people living with HIV to develop leadership skills that can also enhance their employability in workplaces both inside and outside of the AIDS movement. Capacity building and leadership programs have frequently been identified as critical learning experiences that have led to direct vocational benefits. Thus peer based services from an empowerment model could complement a case management approach.

8. **Outreach and Advocacy:** Many participants felt that vocational service providers should play a role in helping to create positive workplaces for people living with HIV by conducting outreach with employers and advocating for improved public policies. These measures can help ensure supportive workplaces for people living with HIV.

9. **HIV Specific Services**: The majority of participants reported feeling most comfortable receiving vocational services from an HIV specific service provider.

These strategies, if implemented, would represent a shift from traditional vocational service provision focused on case management and individualized approaches to those that more readily embody ecological principles. An ecological approach would embody a dual focus on supporting people living with HIV to develop vocationally at the personal level while also

addressing issues of social justice. This would involve a distinct shift towards incorporating an

anti-oppressive approach to practice, empowerment principles, and working on a broader level.

9.4.2.2 A Role for Social Work

Saleebey (2001) believes that appropriate social work theories should address complex

human experiences, guide effective practice, and incorporate the views of social work clients.

Accordingly, this research holds relevance for social work at the practice, research, and theory

levels. As noted previously, social workers are playing an increasingly critical role in the

development of relevant public policy and the delivery of social services to people living with

HIV. Whether employed within AIDS service organizations, through the mainstream social

services framework, or as policy analysts, social work practitioners can potentially have a

meaningful effect on the lives of people living with HIV and their communities. The profession

brings several potential and unique strengths to this field, including an awareness of the

importance of anti-oppressive practice, structural analysis, community development, and a

commitment to theorizing from practice (Fook, 2002; Mullaly, 1997).

Social workers have been active in the HIV field in Canada from as early as 1983;

frequently working within community settings such as AIDS service organizations, community

health centres, social housing providers, and advocacy organizations (Canadian Association of

Social Workers, 1997). The core competencies and skills exemplified in social work are

congruent with this complex work as is the professions' explicit focus on social justice

(Canadian Association of Social Workers, 2005; Mor Barak, 2000). In the increasingly

professionalized field of AIDS work, social workers are often the only accessible and affordable

support available to people living with HIV within community organizations (Worthington et al.,

2008).

In the absence of HIV specific vocational supports for people living with HIV, social workers are frequently providing employment counselling as part of their general caseload responsibilities. Existing evidence suggests that social workers and AIDS service organizations are those most involved in the provision of HIV specific employment supports. For instance in Ontario, 39.5% of AIDS service organizations reported providing employment counselling as part of general case management services (AIDS Bureau, 2009). Similarly, Canadian data indicate that health care professionals are more likely to refer their HIV positive clients to social workers and AIDS service organizations than to rehabilitation specialists for services related to vocational rehabilitation and income support (Worthington, O'Brien, et al., 2009). Unfortunately there is a dearth of literature on social work and vocational issues and no specific models or frameworks to guide social work practice in this area (Leslie, Leslie, & Murphy, 2003).

Given that social workers are often on the front lines of service delivery and are frequently providing employment supports it is critical that their perspective be represented in the development of vocational programs and practice for people living with HIV/AIDS in Canada. Social workers are well positioned to address critical factors at the interpersonal and environmental levels, thus complementing and expanding upon vocational services offered from a counselling psychology perspective. Critical forms of social work practice have traditionally proved compatible with the goals of the community-based AIDS movement. In particular anti-oppressive practice (AOP) stands out as a relevant approach to guide social work practice with communities affected by HIV. Anti-oppressive practice is most salient as it corresponds to the levels of analysis identified in an ecological model while including a distinct conceptualization of oppression and related dynamics. Thus working from a perspective that is informed by AOP principles provides a broad approach that begins to match the complex issues of stigma,

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discrimination, and marginalization faced by many people living with HIV in employment situations (Burke & Harrison, 2002). A social work approach to HIV/AIDS could be organized around four intersecting principles: empowerment, partnership, community development, and public policy reform.

9.4.2.2.1 Empowerment

Effective social work practice provides an environment in which empowerment can develop and where practitioners can partner with people living with HIV/AIDS in challenging the discrimination they experience (Dominelli, 2002; Payne, 2005). Accordingly, a social work practice framework would encompass a shift from counselling psychology models to one that stresses advocacy and human rights. This framework would be based on an interactive and multidimensional understanding of power that views all groups as having the potential to exercise power in achieving their interests (Dominelli, 2002).

Several strategies would distinguish empowering social work practice in the area of labour force participation for people living with HIV/AIDS. As indicated by the study findings, acknowledging and validating the resilience and strengths that are related to living and surviving with HIV is a necessary beginning. As part of daily life, people living with HIV/AIDS negotiate and manage complex social systems and hierarchies in order to ensure adequate health care and income supports. These require a range of self-advocacy skills that were identified in the study findings and which many people living with HIV/AIDS often learn and develop as they progress. These skills proved useful in difficult employment situations as well as in structuring vocational services. Peer support programs and mentorship opportunities may foster leadership skills, facilitate the sharing of knowledge and experience, and assist people living with HIV/AIDS in overcoming difficult employment barriers.

Full implementation of the (GIPA) principles would also be an important characteristic of social work practice in this area. As discussed earlier, the GIPA principles commit service providers to facilitating the greater involvement of positive people in the governance of all structures, policies and programs that affect their lives (International HIV/AIDS Alliance & The Global Network of People Living with HIV, 2010). The benefits of doing so are apparent; successful implementation of the GIPA principles can lead to better programming and increased empowerment for people living with HIV/AIDS (Travers et al., 2008). Finally, recruiting workplace and community leaders to champion the issue of inclusive workplaces for people living with HIV/AIDS can assist social workers in shifting cultural understandings of these issues and in creating accommodating and supportive workplace environments.

9.4.2.2.2 Partnership

In articulating anti-oppressive principles, Dalrymple and Burke (2006), advise that "social problems have a personal, cultural, and structural dimension requiring practitioners to link the personal stories of individuals, groups, and communities to the wider political process" (p.24). As such, social work practice in this area would continue to respond to the personal and emotional needs of people living with HIV/AIDS and affected communities. Similar to counselling psychology approaches, this work requires commitment and a range of competencies including assessment, negotiation, facilitation, critical consciousness raising, and counselling skills . However, a social work approach at this level would also work towards altering client-worker relationships from a "professional as expert" orientation to one involving greater partnership and fuller participation (Dominelli, 2009, p. 52). This would involve power sharing with people living with HIV/AIDS and their communities and increased transparency (Dominelli, 2002; Jeffrey, 2007).

Additionally, a social work approach would engage people living with HIV/AIDS in a process of critical consciousness raising to counter the stigma and discrimination that many study participants identified. In the past this has been identified by other authors as an important role in service provision for people living with HIV (Cain, 2002). In a vocational context this would include joining people living with HIV/AIDS in recognizing and challenging hostile cultural messages regarding social identity, illness, and disability as well as supporting their aspirations for career development and advancement regardless of their social location. Working in this manner requires a deeper reflexivity on the part of the practitioner and a greater standard of client centeredness (Dominelli, 2009). Additionally, it calls for a broadening scope in vocational practice and greater attention to service priorities identified by people living with HIV/AIDS. In particular social work practice would involve organizing HIV specific vocational services within local AIDS service organizations and planning and implementing peer support programs; systemic measures that would support the re-conceptualization of vocational service relationships.

9.4.2.2.3 Intersectionality

Intersectionality suggests that various forms of oppression within society do not act independently of one another; rather these forms of oppression interrelate, creating a system of oppression that includes the impact of multiple forms of discrimination. Social work practice, informed by an understanding of the concurrent personal and structural impacts of multiple stigma and oppression, make it suitable for work in an HIV/AIDS context. Thus, social work practice would contribute a broader and more inclusive analysis of the linkages between various forms of oppression faced by people living with HIV/AIDS in the workplace (Mclaughlin, 2005). Anti-oppressive social work offers an understanding of the multidimensional and fluid

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nature of oppression (Dominelli, 2002), insights into how people construct and are constructed by oppressive social relations (Burke & Harrison, 2002), and a recognition that there may be multiple and diverse constructions within similar situations (Dalrymple & Burke, 2006).

Traditional counselling psychology approaches adapt service models created for mainstream, able populations. In contrast, a social work approach would tailor programs, based on the diverse social realities faced by people living with HIV/AIDS, to recognize and challenge multiple forms of workplace discrimination. In addition to individual work at the personal level social work approaches would recognize the need to work collectively. A key strategy would involve working closely with and actively supporting social justice movements and advocacy organizations involved in cross cutting initiatives to address discrimination and human rights issues for people living with HIV/AIDS and affected communities. Social work practice would also include additional work at the community and public policy level such as outreach and advocacy with employers, support for workplace initiatives to reduce discrimination, involvement in networks and coalitions, and referral and linkages to appropriate community legal supports. To a large degree social workers are already engaged in this work within AIDS service organizations and could expand its focus into a vocational service context.

9.4.2.2.4 Community Development

A broad network of over 150 AIDS service organizations and a related political advocacy movement has been established in Canada for over 20 years. These organizations provide important social and educational services and facilitate a community response to AIDS; as such they "represent a qualitatively different level of involvement than previous reactions to other health conditions" (Freudenberg and Zimmerman in Valdiserri, 2003, p. 9). In order to be accessible and effective, vocational services should be resourced, planned and implemented

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within the continuum of services offered within AIDS service organizations (Escovitz & Donegan, 2005).

Community situated vocational services could build upon the strong presence of social workers already active in these organizations and further contribute to community development processes that would address employment barriers for people living with HIV/AIDS. This would enable vocational service delivery to be integrated with other community programs that address ancillary employment barriers such as access to housing and. Social workers strive to be effective at community organizing and facilitating effective collaboration (Mor Barak, 2000). Thus practice in this area would involve support for the creation of professional networks among AIDS service organizations and mainstream vocational agencies, integration of services and activities within the broader community-based AIDS movement, and the creation of partnerships and coalitions to improve service coordination and facilitate community involvement. Employers and workplaces are, of necessity, considered important influences within community processes and would be, whenever possible, included in community development initiatives. This could include the provision of diversity training for employers, working to increase business investment in community life, and engaging labour unions in HIV/AIDS issues.

9.4.2.2.5 Public Policy Reform

To balance a field dominated by a focus on individual, personal, and psychological constructs, social work vocational practice with people living with HIV would require a focus on public policy reform. Contributing effectively to this level is both a difficult and long term effort and is an area of core competency for social workers. A critical step is policy analysis and research to inform community advocacy and public education. Policy work that contributes to more supportive and flexible public and private income support and disability benefits regimes is

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a pressing priority. The establishment of transitional benefits, income top-ups, increased allowable earning amounts, automatic reinstatement programs, and lifelong medication coverage in all Canadian jurisdictions are policy goals that would improve employment transitions for people living with HIV/AIDS. Developing tools and educational materials regarding HIV/AIDS and employment are key social work activities that would assist people living with HIV/AIDS and employers to better address vocational barriers and may prevent individuals from leaving existing employment.

9.5 Study Limitations

Charmaz (2005) identifies a range of criteria by which constructivist grounded theory studies can be evaluated. These criteria include credibility, originality, resonance, and usefulness. Each of these categories address important questions related to empirical study and theory development. Consideration for the above factors has been an essential component of the research design, and was achieved primarily through reflexive engagement with people living with HIV and allied communities. Adoption of a community-based research framework helped to ensure that the research remains original, authentic, useful, and contributes to community identified priorities for social change. For those who work with people living with HIV on their vocational goals this research has much to offer. Yet at the same time there are limitations. This section discusses the limitations of the research.

The fact that so many participants reported a close connection to AIDS service organizations and the AIDS movement is a likely limitation to the study results. Recruitment for this study took place in partnership with AIDS service organizations and their well established networks. While this contributed to a good sized sample it also meant that most participants were likely well connected within these networks establishing this as a clinically biased sample. In

some cases, interviews were conducted on site within AIDS service organizations including at the offices of a vocational service provider. This may have meant that participants were more cautious in expressing any negative experiences related to service provision.

Theoretical sampling allows the researcher repeated trips to the field to ensure saturation. In this study, three phases of sampling and data collection over a one year period helped to ensure that saturation occurred within emerging conceptual categories. Additionally, a broad diversity of participants were recruited to inform the emerging conceptual framework. This contributed complexity and a diversity of perspectives to the resultant framework. Nevertheless, the perspectives of women, immigrants, and visible minorities were limited to a small number of participants. Additionally, several cultural, racial, gender and class differences existed between the researcher and many of the participants. Power differentials associated to these diverse social locations may have existed could conceivably have served as a barrier in building rapport and thus influenced the interviews. These factors suggest caution when interpreting study findings, particularly those from within diverse populations where additional data is required.

9.6 Future Research

There are three main opportunities for future research into HIV and employment as a result of the findings from this study. The first is in the area of public policy where more research is required in the Canadian context. Specifically, research focussed on the combined impact of income support policies, medication policy, and housing policy on people living with HIV is needed. Secondly, studies that focus on the employment experiences of women, people from visible minorities and recent immigrants would be a valuable addition to the literature. Finally, intervention research that assesses the outcomes and impact of vocational services for people living with HIV would help establish the efficacy of these programs and assist service

providers in planning and delivering the best possible vocational services to people living with HIV in Canada.

9.7 Conclusion

Development of effective HIV/AIDS vocational practice continues to be a dynamic process that involves contributions from several professional disciplines. Research and practice from the counselling psychology perspective has been dominant but is now yielding to integrative and multi-disciplinary approaches. This change is characterized by a progression from a medical model perspective to approaches that consider the structural factors that serve as barriers in the employment experiences of people living with HIV/AIDS. Social work from an anti-oppressive perspective would be useful in further developing effective vocational practice that addresses the issue of labour force participation for people living with HIV/AIDS. This research and the resultant conceptual framework is well positioned to provide the foundations to develop critical interventions that can be used in programs and services designed to assist people living with HIV/AIDS in Canada as they face this challenge.

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APPENDIX A: COMMUNITY ADVISORY COMMITTEE

Kenneth King	Ryerson University	2009-2014
Don Phaneuf	AIDS Committee of Toronto	2009-2014
Tammy Yates	Canadian Working Group on HIV and Rehabilitation	2013-2014
Mary Petty	St Paul's Hospital	2011-2014
LeAnn Dolan	Canadian Working Group on HIV and Rehabilitation	2012-2013
Martine Mangion	Canadian Working Group on HIV and Rehabilitation	2009-2012
Capri Rasmussen	HIV Community Link (formerly AIDS Calgary Awareness Association)	2009-2011

Name of Researcher, Faculty, Department, Telephone & Email:

Brent Oliver, M.S.W. R.S.W.
Faculty of Social Work, University of Calgary
403-220-8676
boliver@ucalgary.ca

Supervisor:

Dr. Catherine Worthington
Associate Professor
Faculty of Public Health and Social Policy, University of Victoria
(250) 472-4709worthing@uvic.ca

Title of Project: Work in Progress: Exploring the Challenges and Facilitators of Labour Force Participation and Programs for People Living with HIV/AIDS in Canada

This consent form, a copy of which has been given to you, is only part of the process of informed consent. If you want more details about something mentioned here, or information not included here, you should feel free to ask. Please take the time to read this carefully and to understand any accompanying information.

The University of Calgary Conjoint Faculties Research Ethics Board has approved this research study.

Purpose of the Study: The purpose of this research project is to develop a better understanding of the benefits and challenges of labour force participation for people living with HIV/AIDS in order to inform the development of vocational programs for people living with HIV in Canada.

What Will I Be Asked To Do?If you volunteer to participate in this study, you will be asked to take part in an interview. During the interview, you will be asked for your experience and perspective on the benefits and challenges related to your participation in the paid work force. The results of the interviews will be used to inform community programs that will help people living with HIV in Canada.

You are free to decide if you want to take part in this study or not. You are also free to not answer questions for any reason, and you may stop taking part at any time during the interview. If you decide not to take part, or you withdraw, it will not change the care and services that you or members of your family receive from any affiliated organizations. If you decide to take part, you will not get any special treatment. Withdrawing from the study means that the researcher may still include information collected before you withdrew your consent.

The entire interview will take approximately 60 to 90 minutes and will be conducted at a time and in location that is convenient for you. The interview will be audio taped and the researcher may take notes during the interview process in order to ensure that the data gathered will be reported accurately. You have the option to decide whether you would be willing to be contacted by research staff after this interview to further discuss the main themes of the research findings. At this time preliminary results will be shared with you and you will be asked for your feedback.

To help cover the costs related to participating in this study, you will be offered $25.00. If you choose to withdraw from the study during the interview, you will still receive $25.00.

What Type of Personal Information Will Be Collected? Should you agree to participate, you will be asked to provide information about your workforce experience as a person living with HIV. Additionally, you will be asked to provide your gender, age, HIV status, socioeconomic status, employment status and ethnicity in order to ascertain basic demographic information.

Are there Risks or Benefits if I Participate? The interview will take 60-90 minutes. There is no physical risk from taking part in this interview. However if you need help dealing with issues raised during the interview, you will be given a resource list with contact information for a variety of telephone crisis resources and community support centres. You may contact any of these service providers in the event that you could benefit from discussing these issues with a professional counselor.

The researcher will not provide any information to authorities unless required by law. For example, if anything you tell the interviewer indicates that a person under the age of 18 is in need of protection, the facilitator shall have to report this to Child Welfare authorities.

Taking part in this study will not give you any health benefits; however your participation may help to advance our knowledge about labour force participation for adults living with HIV. Therefore, participation has the potential to impact future developments of new community programs for people living with HIV in Canada.

What Happens to the Information I Provide?

All of the data collected will be kept in strict confidence. The electronic audio tapes and other data will be kept in computer files that are protected by a password on a secured computer. All of the paper data will be kept in a locked filing cabinet. Your name or other information that could tell others who you are will not be recorded on the audio tapes, computer or paper files. All collected data will be destroyed after five years.

The computer files will be labelled with a code made up of numbers. Only the researcher and his supervisor will be able to see what the code means. When the results of this study are presented they will never use your name or any other information that could tell others who you are. All information will remain strictly confidential and available only to the researcher and his supervisor unless required by law.

Results of this study will form a doctoral thesis which will be presented at conferences and published in a scientific journal. The researcher will not include unique information such as your name so that any publication of results will not identify you. A copy of the final report will be made available to all participating individuals and organizations in this research.

Signatures (written consent)

Your signature on this form indicates that you 1) understand to your satisfaction the information provided to you about your participation in this research project, and 2) agree to participate as a research subject.

In no way does this waive your legal rights nor release the investigators, sponsors, or involved institutions from their legal and professional responsibilities. You are free to withdraw from this research project at any time. You should feel free to ask for clarification or new information throughout your participation.

Participant's Name: (please print) _____

Participant's Signature

_____Date: _____

Researcher's Name: (please print) _____

Researcher's Signature:

_____Date: _____

Questions/Concerns

If you have any further questions or want clarification regarding this research and/or your participation, please contact: Brent Oliver, PhD(C) R.S.W.

Faculty of Social Work, University of Calgary
403-998-5145
boliver@ucalgary.ca

Dr. Catherine Worthington
Associate Professor
Faculty of Public Health and Social Policy, University of Victoria
(250) 472-4709worthing@uvic.ca

If you have any concerns about the way you've been treated as a participant, please contact the Senior Ethics Resource Officer, Research Services Office, University of Calgary at (403) 220-3782; email rburrows@ucalgary.ca.

A copy of this consent form has been given to you to keep for your records and reference. The investigator has kept a copy of the consent form.

APPENDIX C: INTERVIEW GUIDE

Thank you for agreeing to take part in this interview. The overall goal of this project is to identify the benefits, risks, challenges and facilitators to participation in the workforce for adults living with HIV. Your experiences and perspective will be very helpful. The information you provide will help to develop new community initiatives for adults living with HIV in Canada.

You will be asked to read a consent form, and sign it if you agree to participate.

The interview will be audio taped with your consent and the tapes will be destroyed after the study has been completed.

Screening Questions *(Screening questions to be conducted at time of booking and reconfirmed prior to the interview)*

Intro: *Before we begin I would like to confirm with you the following interview criteria:*

1. Are you currently employed and working for taxable income?

2. Have you been in the labour force for the last three months or more?

3. Are you an adult (18 years of age) living with HIV/AIDS?

Guiding Questions

Do you have any questions before we begin?

1. How long have you been employed?
    Prompts:
    - *What has motivated your desire to continue working?*
    - *Has this involved episodes of illness?*

2. How would you describe the type of work you have been involved in?
    Prompts:
    - *Full time / part time / contract / self employed etc.*
    - *Type of work: blue collar / professional / service industry*

3. In general, how would you describe the impact that employment has had on your life and the way in which you experience HIV/AIDS?

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Prompts:

- *Impact on health, quality of life, episodes of illness etc.*

4. What factors played the largest role in contributing to your success in remaining employed?
   Prompts:

   - *What are some skills you may have that facilitate your success in employment.*
   - *Health status?, medication*

5. What are some of the challenges you face (or faced) as a person living with HIV trying to stay in the workforce?
   Prompts:

   - *What might be some personal challenges you have experienced related to health, HIV, medications, side effects, etc.*
   - *What might be some structural challenges? stigma, decreased social support etc.*

6. What are some of the personal or social benefits you gained (or gain) through your engagement in the labour force?
   Prompts:

   - *What might be some personal benefits you gained through work ie: better health, decreased social isolation etc.*
   - *What might be some social or economic factors you gained through work ie: increased resources, better insurance benefits etc.*

7. Are you aware of any risks you face (or have faced) as a result of your employment status?
   Prompts:

   - *What might be some personal or health risks you have experienced related to work ie: increased stress, exposure to illness etc.*
   - *What might be some social or economic risks you are exposed to through work ie: decreased resources, lack of insurance portability etc.*

Next I would like to ask you a few general questions in order to better understand your personal history, and things that may influence your experience of work as a person living with HIV.

8. Did you participate in any formal vocational programs or services as part of the return to work process or while maintaining your employment?

   If so:

   - Can you describe the kinds of supports and services provided by this program?

- Was this program designed specifically for people living with HIV or were they provided by a more mainstream agency?

- What was the most helpful aspect of these services in returning to work or in your continued engagement in the workforce?

- Were there any challenges attributed to your participation in these programs?

- What are the most important service elements in a successful program designed to assist people living with HIV engage in the labour force?

If not:

- Why not? ie: availability, accessibility, cost?

- What has been helpful to you (in the absence of vocational supports) to return to work or successfully maintain your employment.

- What kind of service elements would you have found helpful in a vocational program.

9. Did you access any informal/general supports that assisted you to return to work or maintain employed ie: family, counselor, peer programs.

If so:

- Can you describe the kinds of supports and services provided?

- What was the most helpful aspect of these supports in returning to work or in your continued engagement in the workforce?

- Were there any challenges attributed to accessing these supports ?

10. Did you access services from an AIDS service organization?

if so:

- What kind of services?

11. In what year were you diagnosed with HIV?

12. To which gender group do you identify?

13. How would you describe your racial or ethnic background?

14. What is your current age?

15. How long have you lived in Canada?

- What other countries have you lived in?

- When did you arrive in Canada?

16. What languages do you speak?

17. Do you have a history of injection drug use?

18. What is your educational background?

19. Prior to being diagnosed with HIV, what kind of work did you do?

Summary

Do you have anything else you wish to say about participation in the workforce as it relates to adults living with HIV?

Thank you very much for participating in this interview today. Your responses will help to provide a better understanding of the factors associated with workforce participation for adults living with HIV.

If you feel that today's discussion has raised any difficult issues for you, or if you wish to pursue support or want to talk more about any of the topics discussed today, feel free to talk to the staff at one of the following agencies for more support:

- Toronto/Ontario:
  Don Phaneuf
  Employment Action – AIDS Committee of Toronto
  416-623-1782 ext 8262

- Calgary/Alberta:
  Capri Rasmussen
  AIDS Calgary Awareness Association
  403-508-2500