HIV/AIDS AND VULNERABLE AND/OR MARGINALIZED POPULATIONS IN NOVA SCOTIA: MAKING THE CASE FOR GENDER AND SOCIAL INCLUSION IN PUBLIC POLICIES

Nova Scotia Advisory Commission on AIDS

Atlantic Centre of Excellence for Women's Health

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SECTION I: ENSURING POLICIES AND PROGRAMS MEET THE NEEDS OF THE MOST VULNERABLE AND/OR MARGINALIZED POPULATIONS IN NOVA SCOTIA

Introduction

The Nova Scotia Advisory Commission on AIDS (http://www.gov.ns.ca/aids/) is well-situated to contribute to the development of more inclusive and effective policies and programs, especially for those who are the most vulnerable and at risk of HIV and AIDS. The Commission can speak to the particular populations that it supports and represents and understanding the needs and experiences of people living with HIV or AIDS (PHAs) helps us to understand the challenges facing other vulnerable populations in Nova Scotia for creating inclusive policies, programs and services.

Many organizations, agencies and government departments in Nova Scotia are committed to addressing inequities and understand the need to include those most affected in the development of solutions. In particular, the Government of Nova Scotia has developed and implemented three initiatives, which demonstrate an understanding and commitment to reduce disparities and exclusion and increase inclusion, they are:

1) In order to reduce disparities in health status and respectfully respond to the diversity of Nova Scotians in delivery of primary health care services, the Nova Scotia Department of Health developed: *A Cultural Competence Guide for Primary Health Care Professionals in Nova Scotia* (2005) and *Cultural Competence Guidelines for the Delivery of Primary Health Care in Nova Scotia* (2008). Most recently (2013) the Department of Health and Wellness has developed and is waiting for approval of a document to support diversity and health equity, entitled *Diversity and Health Equity for a Health Action Plan*.

2) To support sustainable community development projects and to raise awareness and consideration of the impact of government's decisions and activities on communities, the Department of Economic and Rural Development led the development of the *Community Development Policy Initiative* (2006) and its companion *Community Development Lens*.

3) In October 2009, the Nova Scotia Government's Diversity Roundtable proposed a plan to focus on integration of diversity into public sector policy development and programming which included embedding diverse perspectives throughout policy development and implementation processes to ensure goals and benefits associated with an inclusive society are realize. In June of 2013, the Nova Scotia Government Diversity and Social Equity Steering Committee are establishing the Diversity and Social Equity Working Groups who will be advising and supporting the Diversity and Social

Equity Steering Committee. The three working groups are: Human Resource Policy and Programs; Corporate Policy; and Multicultural Legislation and Policy. This document can be used to inform the Social Equity Steering Committee in its work.

Using this Document

The purpose of this document is to support and inform policy analysis and program development. By placing vulnerable populations at the centre of policy and program development, we hope this document will:

- Complement existing frameworks by illustrating and reinforcing the need for inclusion of vulnerable populations in the development of policies and programs designed to serve them.
- Provide an opportunity to discuss the complexity of working with and serving vulnerable populations.

The remainder of the document is divided into four parts. It begins with a brief description of two **Conceptual Frameworks** -- social and economic inclusion and exclusion (SEI) and sex- and gender-based analysis (SGBA) – that inform the analysis.

The second section presents a **Scenario,** the story of several "invented" people who represent a range of realities experienced by vulnerable and/or marginalized populations. The intention of the scenario is to illustrate: the complexity and interconnectedness of issues that affect vulnerable populations of women and men, boys and girls, and; the challenges of addressing exclusion and inclusion at both the individual and the community level. This section concludes with a **Summary of Issues** and possible **Discussion Questions.**

The third section provides in-depth **Background** information about eight issues that emerge in the scenario and that affect the well-being of vulnerable and/or marginalized populations: housing; incarceration; addictions and mental health; rural/urban needs; income; nutrition and food security; episodic illness; and navigating 'the System'. It is intended that each of these sub-sections can stand alone as an aid to policy analysis and development as well as capacity building.

The final section of the report identifies a number of additional **References and Resources** to support understanding of and responses to the needs of vulnerable and excluded populations. In developing this document we have drawn from several reports published by the Nova Scotia Advisory Commission on AIDS (http://www.gov.ns.ca/aids/) as well as a range of other reports, websites, and peer-reviewed sources. An extensive reference list is included for your further use.

SECTION II: CONCEPTUAL FRAMEWORKS

This section provides a brief introduction to the two conceptual frameworks that inform the analysis: Social and Economic Inclusion/Exclusion (SEI) and Sex and Gender-Based Analysis (SGBA). Our experience has shown us that SEI and SGBA are essential conceptual frameworks for the formulation and implementation of appropriate and effective public policy

What is Social and Economic Inclusion/Exclusion (SEI)?

Social and economic inclusion and exclusion represent a continuum of individual experience and social reality. Inclusion embodies a sense of belonging and the right to participate in society, while exclusion involves experiences of isolation and segregation. We tend to think of vulnerable and privileged people or populations being fixed in their locations, but any person, population or society can move along the continuum. For example, economic downturn can throw people into unemployment, severely compromising their ability to participate in society or feel welcomed. Finding employment can significantly alter an individual's life experiences and life chances, contributing to their sense of inclusion. At the same time, experiences of exclusion and inclusion may persist across the lifespan and across generations because they are rooted in aspects of individual identity that are generally stable or even immutable. Racialized minorities, gays/lesbians, women, trans-gendered individuals and people living with HIV, for instance, may experience exclusion because of the fears, attitudes and behaviours of others around them, which lead to stigma and discrimination. And, as we know, attitudes and behaviours can be notoriously resistant to change.

While inclusion and exclusion affect individuals, they are also markers of the health and vitality of communities. Inclusion often reflects social cohesion and economic strength in societies. Exclusion signals social dislocation and can contribute to a lack of prosperity. Social and economic inclusion and exclusion represent not only wealth and poverty, but also reflect paucity of opportunities and the realization of individual and social potential. These concepts allow us to explore the complex interactions between social and material well-being and to understand that exclusion has social as well as financial costs.

If we employ a social and economic inclusion/exclusion lens, we can explore a range of influences that affect specific populations – people whose health is jeopardized by chronic or episodic illness; people with disabilities; immigrant; African Nova Scotians; Aboriginal peoples; youth and senior; rural or urban dwellers.

What is Sex and Gender-based Analysis (SGBA)?

Increasingly, we understand that gender inequality contributes to important health and social challenges for women, girls, men and boys around the world. According to the World Health

Organization (WHO) Commission on the Social Determinants of Health, differences in power, privilege and opportunity affect health, and men and women frequently have different degrees of access to these resources for health (Sen, Ostlin, & George, 2007). Efforts to reduce gender inequality are thus critical to improve health and social well-being for women and men as well as whole communities and societies.

In Rising to the Challenge: Sex and Gender-Based Analysis for Health Planning, Policy and Research in Canada, Clow et al outline that from start to finish, the process of SGBA is framed by a recognition that sex, gender, diversity and equity matter at every stage of health research, policy development, planning and practice. In turn, SGBA enables us to anticipate and/or identify biases that contribute to health disparities and, in doing so, to create the possibility of both avoiding discrimination and redressing inequity (ACEWH, 2009).

In order to address gender inequality, we need to understand important differences between the concepts of "sex" and "gender" and to understand their relationship to diversity and equity. "Sex" refers to the biological characteristics that distinguish males and females in any species. In humans, sex differences begin with the chromosomal patterns that distinguish males and females – with males usually having one X and one Y chromosome and females having two X chromosomes. From these fundamental genetic differences, other sex differences in humans arise including variations in body size and shape, the proportion of fat to muscle, which hormones are circulating in the body or at what levels and different reproductive organs. Subtle differences in biochemical pathways, hormones, metabolism and the size of body tissues between females and males may explain some of the known differences in susceptibility to specific diseases or health conditions, such as lung diseases and arthritis. In the case of HIV, women are generally more susceptible to infection due to the physiology of their reproductive systems.

Although we tend to think of sex as comprised of only two categories, male and female, "maleness or femaleness exist and are expressed along a continuum" (Johnson, Greaves & Repta, 2007, page 4). Body hair, a secondary sex characteristic, is a case in point. We generally think of women as having less body hair than men, but many women and men do not fit this stereotype. Similarly, muscular development in both women and men is affected by exercise and diet, but some women are able to develop their musculature to a greater extent than some men due to differences in genetics.

"Gender", in contrast, consists of the socially constructed roles and relationships, personality traits, attitudes, behaviours, values, relative power and influence that society ascribes to the two sexes (Health Canada, 2000). In other words, gender describes and prescribes what it means to be female or male at a given time, in a given society. While we may believe that sex is determined exclusively by nature or biology, gender undoubtedly has a "profoundly social character … [It is] a complex, and powerfully effective, domain of social practice" (Connell, 2000, page 18). Understanding and analyzing the impact of gender on health – and life in general – can consequently pose serious challenges because social processes are both complex and changeable. Today's views on femininity or masculinity, for example, are not the same as

they were a generation ago, nor do these terms mean the same thing in Western culture as they do elsewhere in the world.

Like sex, gender has been typically treated as having two distinct categories – maleness (or masculinity) and femaleness (or femininity) – but, again like sex, this binary division does not adequately capture the range of human experience or the expressions of self and identity that gender encompasses. Few – if any – individuals fulfill the ideals of masculinity or femininity and most of us do not aspire to or achieve one ideal to the exclusion of the other. In other words, most of us experience or exemplify gender as a continuum of characteristics and behaviours rather than as mutually exclusive categories.

While SGBA begins with the variables of sex and gender, it involves more than simply understanding the differences or similarities between women and men. Its purpose is also to illuminate the diversity of experience among women, men and people who identify in different ways. Just as SEI is about more than wealth and poverty, so too SGBA requires a consideration of the many variables or determinants that contribute to or ease vulnerability, such as housing, education, race/ethnicity, sexual orientation, health status, literacy, social supports, employment, and access to services.

SGBA also helps to identify differences among and between women and men, girls and boys that are rooted in social, economic, and political injustices and supports the development of solutions for inequities. It is well documented, for example, that social hierarchies affect who gets ill and the consequences of illness (Labonte, Schrecker, & Gupta, 2005; Raphael, 2004), including who is able to access formal health care, who gives and receives care at home, and who experiences the long-term personal, social and economic impacts of illness. By recognizing that many differences among and between women and men may arise from modifiable factors, SGBA is a resource for developing and assessing tailored responses to gendered and other inequities (Sen et al., 2007, p.2).

Summary

Using SEI and SGBA allows us identify who is most at risk of exclusion and inequity as well as who is most likely to experience significant repercussions of exclusion and inequity. In other words, these frameworks allow us to see more clearly who is most likely to be excluded and why, and supports the development of effective and appropriate policies and programs for those most in need.

SECTION III: MAKING THE CASE FOR VULNERABLE AND/OR MARGINALIZED POPULATIONS

We would like to begin by telling a story. The individuals described in this story are not real people, but their identities and experiences are based on many real stories. The scenario presents several people and their circumstances to illustrate the many faces of social and

economic vulnerable and the ways in which many policies and programs are neither appropriate nor effective solutions to exclusion and inequity.

Scenario

Let's sit in on a support group for people with issues related to housing, social supports, training and education, unemployment or underemployment, and chronic health conditions. This group meets each week at a local community centre in Halifax, Nova Scotia. Among the participants are Sam, Eric, and Mona. Later we will meet Mark.

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Sam, a 30 year old heterosexual man, grew up in rural Nova Scotia and comes from a family with Aboriginal roots that has lived off-reserve for some time. Growing up in a rural community, he did not have access to recreation programs, affordable or otherwise. In his early teens, when Sam and his friends were bored, they began using alcohol and so-called recreational drugs. As they got older, they moved on to harder drugs and eventually injection drug use. Although Sam sometimes used unsafe injection practices, he managed to avoid contracting either HIV or Hepatitis C.

Sam left high school before he graduated and was not able to find and keep a job that provided benefits or paid enough for him to afford an adequate diet and place to live. He was incarcerated in the provincial corrections system for selling drugs on several occasions. In jail, Sam had to undergo periods without drugs and he found it difficult to deal with the withdrawal symptoms, so he tended to seek out drugs in any way he could, including using and/or sharing unclean needles. While he had access to some health care services in prison, he did not use them because he was required to explain to the guards why he needed care and he felt uncomfortable doing so.

After release from his latest sentence none of the shelters would house him because he was still injecting drugs. After two nights in a motel, Sam now lives in a very basic single room. He opted to live in an urban setting to increase his access to services, but this meant he was far from his extended family, causing him to feel isolated. Although he had worried that he would be stigmatized in his home community because of his drug use and time spent in jail, in his new community he experiences this stigma as well as racial discrimination. He has little money for a fresh start, and he is having trouble sorting out the rules governing social assistance that might provide support until he can find a job. Because money is so tight, he has not been eating well and has been forced to rely on the local food bank and the community meal program. Lately, Sam has been feeling more unhealthy than usual. He has no family physician and is reluctant to go to the Emergency Room at the local hospital.

Sam is attending the meeting today because he knows Eric will be there. Sam and Eric became friends at the provincial correctional centre, where Eric was serving a short sentence. Eric is a 48-year old white man who has lived in Halifax for most of his life. He was raised in a small town, but moved to Halifax to go to university and because he felt more comfortable in the city

living as a gay man. He completed a Bachelor of Business Administration with honours, and began work at an accounting firm in his early twenties. Eric was living a comfortable life financially, and had a supportive partner at the time he was diagnosed with HIV. The diagnosis came as a shock; Eric put his life on hold and became depressed. He was able to continue working for a short period of time, but his unpredictable bouts of illness eventually caused him to lose his job. Between the financial and emotional stress, and dealing with HIV-related illnesses, Eric's relationship became strained, and his partner left him. With no steady income, Eric was forced to apply for provincial Employment Support and Income Assistance (ESIA) as well as disability insurance. While this support was welcome, it was not always enough to make ends meet, so Eric would resort to petty theft. He was eventually arrested, convicted, and incarcerated for a few months in the provincial corrections system.

In the correctional centre, Sam and Eric talked about changing their lives. Now that they are back in the community, each faces barriers to finding work, housing, and consistent medical care. They had had limited access to services and programs, such as addiction services and life skills development, that might have helped them make the transition back to their communities. As a result, both men felt completely unprepared for life outside of prison. In fact, other prisoners in the provincial systems had advised them to commit more serious crimes that would send them to federal institution where the programs were better.

Mona, also attending the meeting, is a young, white, heterosexual woman who has finished most of a community college program. She comes from a family that was neither rich nor poor, but that provided her with the necessities of life. She dropped out of college one year before completing her program because she wanted to take a year off to travel. The relationship Mona was in at the time was abusive and it was taking a toll on her self confidence. In addition, she could not find steady work and moved in and out of the formal labour market, barely making ends meet. At the age of 25, she is unemployed again.

During her periods of unemployment, Mona became more isolated from her social network and lost the financial benefits that her previous job provided. The psychological impact of her abusive relationship and feelings of isolation led her to depression and then her substance abuse issues escalated. She got referred to a community mental health clinic but was wait-listed for services. Running out of options to feed her drug habit and support herself, and feeling too embarrassed to apply for social assistance, Mona began offering sex to friends in exchange for meals or a place to stay. Eventually, these "friends" referred her to strangers and Mona found herself involved in sex trade. Mona was recently tested and diagnosed as HIV positive, but she has not yet sought further medical care. She has not been incarcerated to date, but she has had some close calls with some clients and the law, and, in one instance, a conditional discharge required her to avoid some neighbourhoods, including those where she could get support services. She has been in and out of women's shelters and she has lived with an acquaintance or two, but she has not been eating well. She has lost weight and feels weak. She looks forward to the group meeting for a quiet place to relax and for some nutritious snacks.

Mona needs financial and social supports in order to leave the sex trade and find a way back into the community. Her family and friends have fallen away and aren't sure they can trust her. She wants to stay away from some of her old contacts and be healthy. She needs a safe place to live, where there is access to methadone treatment, and the means to support herself. She is also anxious about people knowing that she is HIV positive and about her past. Feeling that she has burned a lot of bridges, she is not sure she can mend her relationships. She feels like she was expected to finish school, have a good job and contribute to her community. Instead, she is starting over.

While Sam, Eric, and Mona are talking about access to housing and social support through the community centre group, Mark is standing outside the door. Eric and Mona both agreed to attend the support group because of positive experiences with their community workers, who used a non-judgmental and client-centred harm reduction approach. This positive experience gave them confidence to try out the group, and trust that they would feel as included and safe as they did in their one-on-one sessions. In fact, the match was so positive, that Eric chatted with one of the group facilitators about options to include his friend and thus he was able to encourage Sam to seek a referral from one of the participating community agencies.

Mark has not had positive experiences with community workers, but heard about the group from others at a shelter where he stays occasionally. Mark decided he would check out the group today, but as he caught glimpses of the people who went inside, he realized he would be the only African Nova Scotian attending. He worried he might not be able to relate other group members, and decided to leave and try going another day. Meanwhile, Eric, Mona, and Sam have begun looking forward to the support group; it helps them find their way through the system to get services they need, but it also helps them feel connected to a community again.

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Summary

This scenario highlights many challenges faced by vulnerable populations in Nova Scotia. Some of the main issues include:

- Housing
- Incarceration
- Addictions and Mental Health
- Rural/Urban Differences
- Income and Unemployment
- Nutrition and Food Security
- Episodic Illness
- Navigating the System

More information on each topic is outlined in the following section. While specific topics are dealt with separately, it is important to keep in mind the inter-connectedness of all eight issues as well as overarching dynamics that cut across all the topics, such as service coordination and

continuity of care. For example, persons living with HIV/AIDS (PHAs) frequently require complex combinations of health and social services (Pyra Management Consulting Services Inc., 2005). However, the system is often confusing for consumers; there is no single point for PHAs to access all the services they need, so they often miss out on some of the available benefits. Without coordinated services, PHAs become more affected by each of the issues listed above.

Discussion Questions

To stimulate discussion and have more in-depth analysis of the scenario and how it relates to the policy-making process, we have developed the following questions for your consideration. We recommend using the resources available in Section IV to assist you in thinking about these questions.

1. Recognizing that differences in power shape what issues get attention and are acted on, key questions to ask include: What problem has been identified? Who is getting noticed in the media, in the community, by policymakers? Who is on the 'winning' side; on the 'losing' side?

2. Searching out a diversity of viewpoints is vital to building effective responses, key questions to ask include: What discussions, evidence, and resources are you using to understand sex, gender, diversity, and equity in your policy context?

3. Accessing research and data on the social determinants of health gives a more holistic understanding of the challenges and obstacles that marginalized populations may be facing, key questions to ask include: What quantitative and qualitative data are available? Are data disaggregated by sex, ethnicity, income, etc.? What isn't the data telling us and where else can we search for information?

4. Being aware and inclusive of those populations that are marginalized is crucial when determining which concerns should be prioritized. Key questions to ask include: Whose needs are recognized and how have recommendations been framed? Are recommendations aimed at equality of opportunity or equity of outcome? Or both?

5. Funding, planning and implementing strategies are when policymaking becomes visible to communities, key questions to ask: How are programs and projects chosen? How are funds distributed? How are partnerships developed?

6. Sharing comparative knowledge and experiences promotes new ways of learning and doing, key questions to ask include: How will your lessons be shared with beneficiaries, partners, researchers, organizations, other policy makers, and/or publically? Are knowledge products widely and easily accessible to those within the community and to partners?

SECTION IV: BACKGROUND ON EMERGING ISSUES

The following discussion unpacks several key issues presented in the scenario. While the issues are discussed separately, it is important to remember they are linked by experiences of inclusion and exclusion, stigma and discrimination, inequity and vulnerability. These cross-cutting themes will become apparent in the analysis of issues.

Issue 1: Housing

Having access to safe and affordable housing is a significant predictor of a person's health as well as her/his access to health care services. Homelessness and unstable housing contribute to HIV transmission and have been linked to inadequate HIV care and poor health outcomes. ("OHTN", 2012)

Nova Scotia's health care system is based on the assumption that everyone has a safe, clean place to live, where they are accessible by phone and mail, where they can prepare food and store medication. Unfortunately, this is not a reality for many Nova Scotians (Community Action on Homelessness [CAH], 2009). As highlighted in *Rising to the Challenge*: "Asked to describe what factors contribute to good or poor health, women with low incomes repeatedly mention bad housing, including having to cope with lack of heat, mold, mice, rats, lice, dangerous neighbourhoods, harassment from landlords and the threat of violence. Women also consistently describe how the stress and physical deprivation caused by struggling to afford a good place to live contributes to their weakened mental and physical health (ACEWH, 2009:104)."

Many factors influence a person's ability to find stable housing. In 2009, CAH found that:

- 67% of the homeless population in Halifax remain homeless because they cannot afford rent, they are unemployed, or their income is too low ;
- 36% remain homeless because of mental and physical health conditions and addictions
- 24% do not have suitable housing options;
- 21% because they experience discrimination due to a criminal record, being a welfare recipient, etc.; and,
- 17% cannot find adequate supports to find housing.

Finding affordable housing can be an issue for any low-income person, but when the person is dealing with additional issues, like Eric and Mona with HIV/AIDS or Sam with a history of incarceration, housing becomes that much more of a challenge. "Homelessness – having no housing at all – is certainly bad for health, and homeless women and men are at much greater risk of respiratory diseases (pneumonia, colds, tuberculosis, asthma), arthritis, rheumatism, high blood pressure, diabetes, lice and scabies" (ACEWH, 2009:

104). Of the people surveyed in a CAH report on Halifax homelessness, 80% indicated they had at least one chronic health condition, and 23% had more than six (CAH, 2009). Having a chronic health condition without adequate housing is a major issue. Eating a nutritious diet is also more difficult, as is exercising regularly, sleeping well and safely, keeping clean, accessing health services, filling prescriptions, and storing medications.

In 2004, the Positive Spaces Healthy Places (PSHP) project in Ontario emerged as the first community-based and province-wide longitudinal study in Canada (PSHP, 2004). One segment of that study compared people living with HIV/AIDS (PHAs) who had stable housing to those who did not have stable housing, i.e., they had to move several times per year. They found housing instability was associated with lower levels of education, unemployment, history of incarceration, homelessness, and housing-related discrimination. Unstable housing was also associated with significant negative effects on physical health (lower CD4 counts, higher viral loads, and higher mortality rates), mental health (depression, stress, addictions, and substance abuse), access to services, and adherence to treatment. Safe and affordable housing was correlated with better mental health, better access to health services, and fewer experiences of stigma/discrimination. The results of this study have since been corroborated by other research, including a systematic review (Leaver, Bargh, Dunn & Hwang, 2007) and two large scale American studies similar to PSHP (National AIDS Housing Coalition [NAHC], 2008). Some of these studies expanded upon the issues of living with HIV/AIDS, and having inadequate housing. PHAs in need of housing are more likely to delay seeking health care, have less access to regular care, are less likely to be receiving optimal therapies, and less likely to adhere to HIV treatments.

A person with a history of incarceration, or who is transitioning into the community after incarceration can face many challenges when it comes to finding adequate shelter. In a 2008 report on reducing the risk of HIV and Hepatitis C in correctional facilities by Marshall many of the focus group participants who had been incarcerated reported feeling unprepared for the transition to the community (Marshall, 2008). Making appointments with the Employment Support and Income Assistance (ESIA) program was difficult prior to release, which made it challenging to arrange income support benefits upon release. This left them without places to stay for their first nights out of prison. If an offender does not have support from ESIA, they do not have the money to give a landlord a deposit. Without an address, they cannot get their ESIA cheques; without the cheques, they cannot pay for a place to live. This spiral of logistical challenges is compounded by landlords refusing to rent to ex-prisoners, and to those on ESIA. Many of the former prisoners who did find accommodation said they were living in "rat-infested slums." (Marshall, 2008 p.28)

For those struggling with housing issues, or who are homeless, government assistance would go a long way in helping them find a stable place to live. According to Community Action on Homelessness (2009), 35% of people living on the streets in Halifax do not receive any government services because they do not have addresses that allow them to qualify for benefits. At the same time participants in

the study by Marshall (2007), focusing on the experiences of persons living with HIV/AIDS on income support, repeatedly discussed the inadequacy of ESIA benefit levels. The participants explained housing allowances for a person on ESIA were insufficient to obtain safe, clean, and affordable places to live, and the annual inflation of housing costs were not reflected in increased benefit levels. These are issues common to any low income person looking for affordable housing with ESIA benefits, but when living with a chronic disease such as HIV/AIDS, the challenges become greater. Because HIV affects the immune system, it is critical that PHAs have access to hygienic living conditions where they can get a healthy amount of rest, and have access to healthy foods, supplements, and drug treatments. Extra income support benefits for people with special health needs are not always provided and/or sufficient.

Inadequate housing and/or homelessness overlaps with many other marginalizing factors, such as the stigma associated with HIV/AIDS, poverty, mental illness, drug use and incarceration, as well as gendered and racialized discrimination (NAHC, 2008). Better housing can help to reduce marginalization and decrease social exclusion (NAHC, 2008; Positive Spaces Healthy Places, 2009). Improving housing policy and programming by framing and structuring them as public health interventions has been shown to reduce public spending, make better use of public dollars, and decrease health disparities (NAHC, 2008). Positive Spaces Healthy Places recommends creating housing programs for PHAs that address the social determinants of health, which would then decrease social exclusion.

The Housing First model is one program based on the belief that housing is a basic right, and providing a person with housing can create a foundation for them to begin recovery from addictions and/or mental illnesses. The program provides an apartment to consumers without requiring them to enter substance abuse or psychiatric treatment. Services are also offered by a multidisciplinary team of professionals, but using them is not mandatory. The only requirements for the program are: tenants pay 30% of their income and participate in a money management program, and meet with a staff member at least twice per month (Tsemberis, Gulcur, & Nakae, 2004). An example of a Halifax based program is Halifax Housing Helps (HHH). HHH works with single individuals with complex and on-going barriers to housing stability. These individuals may regularly access the HRM shelter system, drop-in services, and other community agencies and services.

To suggest more specific policy improvements, we can look to the report completed by Marshall, Income Support and HIV/AIDS: The Experiences of Persons Living with HIV and AIDS in Nova Scotia which recommended that the Department of Community Services (DCS) increase housing allowance rates to reflect the actual cost of rent/housing and power, and index the rates to the cost of living. (Marshall, 2007) The PHAs also recommended that the DCS's Housing Division work to ensure a sufficient amount of safe and affordable housing in the province. Exploration of a more effective response to poor landlord practices, improvement of the safety of boarding houses, and an analysis of measures to

counter landlord rental increases to meet social assistance shelter rate increases

(including the imposition of rent controls) were also suggested.

Issue 2: Incarceration

unemployment and race (Fazel & Baillargeon, 2011). Research also suggests

In Nova Scotia, individuals who receive a sentence length of less than two years are incarcerated in one of five provincial correctional facilities; if the sentence is over two years, they are sent to a federal facility. Literature on correctional facilities in Nova Scotia is scarce; however, two recent reports scrutinized the provincial correctional system for its lack of programming (Kitchin, 2005; Marshall, 2008). Because there are so few resources, the information gathered here comes mainly from those two reports, as well as two other research studies that have examined the incarceration experiences of female and/or male prisoners in provincial jails in Atlantic Canada (Bernier, 2010; Bernier & McLellan, 2011).

Prisoners experience disproportionately high levels of both physical and mental health issues, including chronic conditions, infectious diseases (including HIV/AIDS and Hepatitis C), and mental health issues (Correctional Services Canada, 2004). A recent study examining the health status of female and male prisoners in a provincial jail in Atlantic Canada found that females report more mental and physical health issues than males, as do Aboriginal prisoners compared to non-Aboriginal prisoners (Bernier & McLellan, 2011). The high prevalence of health problems among prisoners has been attributed to social and economic characteristics linked to poorer health in the general population, including poverty, low income, low education,

that features of the prison environment impact the physical and mental health of prisoners, including violence, overcrowding and isolation (Council of Scientific Affairs, 1990) as well as lack of natural light and fresh air, unhygienic living conditions, limited physical activity, unsafe drinking water, and diets lacking basic nutrition (Bernier & McLellan, 2011).

As discussed in a 2008 report from the Nova Scotia Advisory Commission on AIDS, *HIV and Hepatitis C in Correctional Facilities: Reducing the Risks*, prisoners are supposed to retain their human rights and have access to health services while incarcerated. However, few services, programming and supports exist in jails to address the health (and other) needs of provincially incarcerated women and men in Atlantic jails (Bernier, 2010; Bernier & McLellan, 2011; Marshall, 2008). Given the lack of supports available in provincial correctional facilities, prisoners are cycling in and out of the system without sufficient intervention for drug rehabilitation, education programming, job skills training, tools and education to practice safe sex, or any kind of transitional planning and preparation for returning to the community (Bernier, 2010; Kitchin, 2005).

Alcohol and substance use is pervasive among provincial prisoners. One recent

study from the Atlantic Region found that 93% of male and 90% of female prisoners reported alcohol and drug use prior to incarceration (Bernier & McLellan, 2011). Addressing drug addictions was one of the more significant issues discussed among prisoners in the *HIV and Hepatitis C in Correctional Facilities: Reducing the Risks* report. When opiate-addicted prisoners, like Sam, are admitted into a provincial facility, they often face inadequate treatment for their addiction. Prisoners described several issues including "inhumane" weaning off narcotics upon admission; refusal to initiate methadone maintenance treatment (MMT) upon admission; extensive waits/delay in access to MMT (3-4 days); refusal to continue MMT for those already on MMT; dramatic drops in methadone dosage levels upon admission; rapid weaning from MMT upon release; and, no transfer to MMT programs in community upon release (usually because there are long waiting lists). Without sufficient and consistent access to MMT while incarcerated, and no access to pain medication to ease symptoms of withdrawal, prisoners are often driven to find drugs in any way they can, which means higher incidences of unsafe injections.

The culture and living conditions of incarceration promotes risk-taking behaviour such as unsafe drug injection use, tattooing, piercing, and sexual activity. Risky behaviours are exacerbated by inadequate or lack of health and addiction-related programming, and places prisoners at particular risk for blood borne pathogens such as HIV and Hepatitis C.

In our scenario, Sam had not accessed health services while incarcerated, which could be a major issue considering the risks he has taken with his health. Health services were available to him in jail, but there were significant barriers to accessing such services. In the provincial system, prisoners must make health services requests to the guards to see a health professional. Prisoners are sometimes not comfortable making a request because there is a lack of confidentiality; they often have to explain the reason for the visit with correctional guards, who then determine the severity and urgency of the issue (Bernier & McLellan, 2011). HIV testing is available on a voluntary basis, but prisoners have said they don't believe the test results are confidential, so some are reluctant to get tested.

According to former prisoners, a successful transition to the community requires a strong drive to help yourself because there is little or no support otherwise. Without any services, prisoners are much more likely to re-offend; they are re-entering the community in the same condition they left, but now with a criminal record. Once they are back in the community and stigmatized with a criminal record, they are more likely to have greater challenges in returning to work or finding work, securing adequate housing, or accessing the social support they had before incarceration. All of these factors heavily influence the likelihood of returning to jail.

Prisoners with a chronic disease have a greater need for services that help them integrate back into the community and, in the case of HIV or other communicable diseases that help prevent transmission to others. They also require extra resources for medications, nutritious food and supplements, and safe, clean housing. Eric

would have benefited from a reintegration or transition program designed to help him find a place to live and to arrange for income assistance prior to release without having to go through the stress of being homeless, couch surfing, and waiting for his payments to come.

We also see how the lack of programming affects Sam. He has been cycling in and out of the provincial prison system without access to a program that would help him transition back into the community, end his drug addiction, find stable housing, find employment, and not rely on drugs for income.

Based on the issues in Nova Scotia's correctional facilities, the authors of the corrections report recommended a Blood Borne Pathogens Prevention and Implementation Strategy be developed for corrections facilities, which would address prisoner access to:

- Methadone maintenance treatment;
- Clean needles/tattoo equipment;
- Safer sex tools;
- HIV/Hepatitis C prevention education;
- Confidential health/sexual health
- Counselling;
- Testing and counselling;
- HIV/Hepatitis C treatment;
- Transition support to re-enter the community

The report also recommended ensuring prisoners have access to Methadone Maintenance Therapy (MMT), HIV/Hepatitis C treatment and any other necessary health supports and services while in the provincial correctional system. Prisoners also need better access to sexual education and HIV/Hepatitis C preventions programs. Finally, the authors recommended enhancing pre-release/discharge planning to promote successful reintegration of prisoners into their community. All these suggestions should be part of an enhanced prison health initiative being explored by the provincial government (Marshall, 2008).

Issue 3: Addictions & Mental Health

When experiencing the kind of marginalization similar to that faced by Eric, Sam, and Mona, day-to-day life carries a lot of stress. Stress can come from figuring out how to maintain a steady income, finding housing, employment, staying healthy through chronic illness, experiencing stigma and discrimination, etc. Stress influences your overall health, particularly mental health. Mona is the only person in the scenario who has a diagnosis of depression, but Eric is experiencing multiple stressors and may have undiagnosed mental health issues. We can also see how Sam's life is affected by his addiction.

Mental health is defined by the Mood Disorders Society of Canada as having a balance of mental, emotional, physical, and spiritual health. Mental health is influenced by factors such as having caring relationships, a home, belonging to a supportive community, and work and leisure time. It is also affected by having solid coping skills to deal with every day ups and downs. When a person has a mental illness, they experience "a serious disturbance in thoughts, feelings, and perceptions that is severe enough to affect day-to-day functioning." Women, Aboriginal peoples, homeless people, and prisoners are among the most vulnerable groups in society and they are more likely to develop depression. Women are twice as likely as men to be diagnosed with depression, and mental illness among prisoners in one Canadian city has been measured as high as 92% (Mood Disorders Society of Canada, 2010).

Receiving an HIV diagnosis is emotional and stressful; without trained and sensitive health professionals, a diagnosis could have damaging psychosocial effects (MacLean, 2006; Pyra Management Consulting Services Inc., 2005). Over 40% of people living with HIV/AIDS experience depression some time during their illness (CATIE, 2010). Susceptibility is higher for various reasons, such as HIV medications, hepatitis C treatments, dealing with physical effects of the disease itself, experiencing social isolation, stigma/discrimination, or having dealt with prolonged drug use (CATIE, 2010). Depression is particularly difficult for PHAs because it affects the body's ability to fight the virus, it may affect a person's ability to care for themselves, and could interfere with adherence to treatments, or lead to risky behaviours such as alcohol abuse or unsafe sex (CATIE, 2010).

Addictions and mental health conditions are often concurrent; however, it is important to recognize the two are not synonymous. For example, Mona struggles with depression, which contributes to her drug addiction; however, Eric has mental health issues associated with stress over his diagnosis, but does not have an addiction. Addiction is defined by the Mood Disorders Society of Canada as either psychological or physiological dependence on a substance, such as prescription medications, alcohol, illegal drugs (cannabis, opiates, cocaine), steroids, or inhalants. However, either and both conditions carry with them its own type of stigma and discrimination. (Mood Disorder Society of Canada, 2010)

Substance abuse is highly prevalent in the correctional system, and, indeed, is often the reason for incarceration. But this also means that the correctional system is an important point of intervention. The prisoners interviewed for the study, *HIV and Hepatitis C in Correctional Facilities: Reducing the Risks*, recognized rehabilitative programming as a crucial service to prevent re-incarceration. One participant commented, "Many inmates are willing to take programs so they can change, but there are no programs being offered in the provincial prisons. In the end, people are released and go and do similar mistakes, which bring them back in." Some commit more serious crimes in order to get in the federal prison to access federal programs. Based on the findings from the discussion with prisoners, the authors of the report recommended that Methadone Maintenance Treatment (MMT) programs be implemented in Nova Scotia's correctional facilities immediately. The programs should be extensive enough that each prisoner with an opiate addiction would be able to receive MMT upon admission on both an initiation and continuation basis.

Nicotine addiction is as much as two to three times more prevalent among PHAs compared to the general population (Lifson et al., 2010). This is a significant concern because smoking can affect HIV treatments, but also because the diseases that occur more often in smokers have further increased risk among PHAs. For example, PHAs are at higher risk of developing lung cancer even if they do not smoke, but if they do, their risk is further increased (Lifson et al., 2010). Smoking also increases risk of co-morbidities and mortality in PHAs from diseases such as cardiovascular disease, non-AIDS cancers, and bacterial pneumonia.

Issue 4: Rural/Urban Contexts

According to many studies, living in rural Canada places people at a distinct disadvantage when it comes to health, income, access to services and other determinants of social well-being and health. Some of the most profound inequities can be found when comparing health outcomes for people living in rural versus urban Canada[1]. For example, rural Nova Scotians have lower economic prosperity, social well-being, education attainment, health care access, and health status than urban Nova Scotians (Rural Communities Impacting Policy, 2003; Langille et al., 2008). Not only do more people live rurally in Nova Scotia as compared with other parts of the country, but this province has the highest income disparity between rural and urban communities (Hayward & Colman, 2003).

Geographic barriers are an obvious challenge facing those who live in rural communities. Rural residents of Nova Scotia are concerned with the lack of access to health services and the shortage of rural health care practitioners, and indeed, 7% of rural Canadians live more than 25 km from their nearest physician, and farther still from specialist care (Mitura & Bollman, 2003). If you live rurally and have a low-income, and/or do not have access to a car, access to health care services becomes even more difficult. While small town/rural areas may provide more social supports, issues around privacy and confidentiality may be in question.

Social, cultural, and environmental differences also contribute to poorer health outcomes. Living in a small community has its benefits: social support can be high when everyone knows each other and can provide community support. However, if the cultural environment within a community is not open to diversity, individuals who do not "fit in" can become marginalized. We can see some of the social and cultural effects living rurally have on Eric's health. As a gay man, Eric did not feel comfortable or accepted living in his home community. He most likely experienced feelings of isolation, high stress, and the available health services and information were not relevant to his needs nor provided confidentially. After he moved to Halifax, he felt more comfortable living as an openly gay man, and was able to access confidential health services, but he had to isolate himself from his family in the process.

Despite acknowledgement of the multiple issues associated with living with HIV/AIDS in rural Canada, research on the topic is scarce. Geographic barriers to services are especially problematic for rural PHAs, who must travel regularly, and often long distances, to urban centres for health services. A few authors have explored experiences of rural PHAs, and found that stigma, conservative values, and beliefs that HIV/AIDS is not an issue in the community are common to rural areas and can isolate a person living with HIV/AIDS (Veinot et al., 2008). Compared to urban-dwellers, PHAs

[1] Statistics Canada defines a rural community as an area populated by 10,000 people or less. Based on this definition, an estimated 37-50% of Nova Scotians live rurally, compared to 20% of all people in Canada. However, other definitions have counted up to 75% living in rural Nova Scotia.

in rural areas have been found to experience more discrimination, more loneliness, coping difficulties, and barriers to health and social services (Bella et al., 2008; Heckman et al., 2004). In Heckman et al.'s study, over 60% of rural PHA participants reported symptoms of depression, yet had less access to mental health interventions than urban-dwellers. Bella et al. (2008) found PHAs in rural Newfoundland, Ontario and BC were less likely to disclose their HIV status to others or seek local services because of overlapping relationships with community members (e.g., staff at health clinic could be family member of a friend) that would affect confidentiality.

The internet is an important resource for rural PHAs to access peer support, and in some areas of Newfoundland they can use the internet to connect with their health care providers. However, some are not able to afford internet access, and/or do not feel comfortable accessing it in public spaces. Many sites provide information better suited to high speed internet which is not always available in rural areas.

Access to scientific evidence and information on HIV/AIDS is more difficult for rural populations, and the information that is available may be interpreted in a variety of ways according to the culture and notions of acceptable moral behaviour within the community (Bella et al., 2008). In addition, a recent study by Langille (2011: S109) noted that "physicians in [a] rural community in Nova Scotia do not always provide preventative advice to adolescents in their practices about sexual health in accordance to with accepted professional guidelines". Because all of these other factors are also integral to rural well-being, increasing the supply of practitioners and health services alone will not provide a long term solution.

Reports on rural Nova Scotia youth have pointed out that growing up rurally results in less access to recreational programs and health education, as well as few youth employment opportunities, boredom, and isolation. According to a report on African-Nova Scotian youth, there is less chance the programs that are available to African-Nova Scotian youth would reflect their culture and history. These youth also deal with racism, generally feeling like they don't belong, with fewer role models, and not having their needs met through the community or school system (Kelly, 2003). African Nova Scotian students who live and attend schools in rural Nova Scotia often have higher high school drop-out rates than urban students, which has been attributed to being visible minorities in the school, having fewer role models (e.g. teachers), and the curriculum and school resources not including learning about their own culture and history (Kelly, 2003).

Issue 5: Income

Finding jobs that provide a steady and adequate income can be a challenge in Nova Scotia, but it is particularly difficult when you are part of an excluded population.

Statistics Canada measures poverty based on the low income cut-off (LICO), which accounts for family and community size. For example, the LICO for a family of three living in Halifax would be low-income if their income after tax was under $22,516, whereas the same family in Yarmouth would have a LICO of $19,932 (Government of Nova Scotia, 2009).

Poverty cuts across all different populations, but specific groups are more vulnerable in Nova Scotia. These include: women; persons with disabilities and/or chronic illness; single individuals; lone-parent families, which are overwhelming female-headed; older individuals; Aboriginal people; African Nova Scotians; immigrants; and, people with low educational attainment, especially those who did not complete high school (Government of Nova Scotia, 2009). People who fall under more than one of these categories may experience compounded effects of poverty and marginalization. For example, Mona, as a woman is disproportionately affected by poverty; Sam is Aboriginal, single, and has poor educational attainment; while, Eric has a chronic disease that prevents him from working and he is single.

To demonstrate how poverty can affect or be affected by other factors, we can look at the interaction between poverty and HIV/AIDS. According to the Canadian AIDS Society (2006):

- Poverty is a key factor causing people in Canada to be vulnerable to HIV infection.
- People diagnosed with HIV face many barriers when attempting to gain, maintain, or establish economic security.
- Persons living with HIV/AIDS who experience poverty or economic insecurity are at risk of having their disease progress quickly and of having a lower quality of life.

Benefit levels are inadequate to enable Nova Scotians, particularly those with specific health needs like PHAs, to cover daily needs such as safe and clean housing, transportation costs, eating healthy foods and taking various vitamins/supplements, dental and medical costs (including drugs), phone costs, costs of education or return to work, and extra money for leisure time activities (Marshall, 2007).

According to an unpublished 2009 affordability scenario, a lone woman living with HIV in Halifax would require $1083.69 to cover her basic needs each month. However, a lone woman on income assistance would have received $638.52, leaving a deficit of $445 per month. A lone man in the same situation would have a deficit of $509 per month. One participant in a study by Marshall (2007) remarked on the insufficient funds provided by social

assistance: “Poverty has made me go to extremes (to get food) that were once below my level of dignity…You scam, con, steal from the grocery store, or mooch from family and friends. Sometimes you just go hungry and this is when cigarettes come in handy.” Another participant reflected that “If you lose your dignity, you lose your self esteem and life just becomes survival” (p. 27).

Based on their discussions with PHAs on ESIA, the authors of the Marshall (2007) report recommended the provincial government implement policies that increase the basic personal and special needs allowance rates for individuals on ESIA to accurately reflect the costs of living, which could be calculated annually based on evidence collected through organizations such as the Atlantic Health Promotion Research Centre. In addition to increasing the basic personal and special needs the report recommended other items be considered for regular coverage under ESIA such as vitamins and supplements, and transportation to medical appointments. The Marshall (2007) report also identified, through clients’ experiences, that the process of gaining access to benefits was a struggle and that income assistance staff were inconsistent in offering the extra benefit. One client explained: “The attitude in the staff comes across as if they are giving you money out of their own pockets, which forces the client into a position of anger.”

It was also recommended that reducing barriers to finding and retaining employment for PHAs and any individual on ESIA, living in poverty and/or dealing with a chronic and/or episodic illness would also be instrumental to improving their income security. (Marshall, 2007)

Issue 5: Nutrition and Food Security

"Food security exists when everyone has access to safe, nutritious food of the variety and amount that they need and want, in a way that maintains their dignity." ("Food Security," 2012)

Good nutrition is one way by which persons living with HIV (PHAs) can have a positive impact on their general health and treatment path. Nutrition supports and strengthens proper functioning of the immune system, which can be compromised by HIV infection. However, good nutrition and food security are compromised because often other factors associated with HIV such as poverty, addictions and stigma intersect.

For the Nova Scotia based Activating Change Together (ACT) for Community Food Security project at Mount St Vincent University, community food security has been defined as "a condition in which all community residents obtain a safe, culturally acceptable, nutritionally adequate diet through a sustainable food system that maximizes community self-reliance, and social justice." (Hamm & Bellows, 2003)

The Ontario HIV Treatment Network (OHTN) led research project has approached the issue of nutrition for PHAs from the perspective of general food insecurity, which is defined as the uncertain or limited availability of nutritionally adequate or safe food, or the inability to procure food in socially acceptable ways." (Andersen, 1990) They are examining the health outcomes of PHAs and the various dimensions of food insecurity, such as:

- The amount of food to meet personal nutritional requirements,
- The safety and quality of the food, and
- An ability to acquire the food in socially acceptable ways (as opposed to stealing, begging, engaging in sex work, and drug dealing in order to procure food).

Food insecurity has also been linked to lower CD4 counts, reduced drug adherence and effectiveness, incomplete HIV viral suppression, and increased risk of mortality. (Andersen, 1990; Weiser, Frongillo, et. al, 2008; Weiser, Brandson, et. al., 2008; Gillespie and Kadiyala, 2005).

Income is one of the most important determinants of food security. Research has shown that Nova Scotians who live on social assistance or minimum wage earnings cannot afford to eat well, no matter how carefully they choose and prepare food. According to Marshall's report, most PHAs could not extend their budget to cover food for the entire month and could not afford to purchase the more nutritious and expensive perishables of fresh fruits and vegetables. The cost of a nutritious diet is prohibitive. Most PHAs reported regularly choosing between paying rent and buying food. (Marshall, 2007)

If dependent on social assistance, there are often difficulties associated with many of the current solutions and/or resources for food security. For example, the Social Assistance allowance for food is included within the category of Personal Allowance.

Based on the Nova Scotia Food Costing Project, it is obvious that the true cost of food is not covered by the Social Assistance allowance for food. (Participatory Action Research and Training Centre on Food Security, 2010)

In Nova Scotia, according to Marshall's report, even with the extra special nutritional allowances, many find that the other fixed expenses (e.g. rent) and unexpected demands force clients to use the food allowance to cover these other expenses (Marshall, 2007). Therefore people living with HIV and AIDS, who are on social assistance in Nova Scotia are receiving insufficient funds to meet their basic needs and are vulnerable to homelessness, and/or poor living conditions, and food insecurity, often relying on the charitable food sector for temporary food relief.

However, according to recent research, the charitable food sector in Canada is not equipped to address food insecurity and the nutritional needs of people living with HIV; often lacking fresh produce and dairy which is a necessary to avoid negative health implications. (Miewald, Ibanez-Carrasco and Turner, 2010)

In addition, food banks, if they exist locally, may not always be accessible in a number of ways (e.g. location, wait times) or provide nutritious alternatives suited to the PHAs' needs on their food bank day. Community meal programs may have similar barriers, as well as complications around pill taking and meal times plus having to share an eating place when personal privacy and safety may be concerns.

Another option is sharing meals with friends and family but this may be limited due to availability and/or potential strain on relationships over time, and again presents problems of taking pills and requiring a particular diet, when one may not have disclosed one's HIV status to everyone around the table. Meals within correctional institutions would have many of the same issues.

To suggest more specific policy improvements, we can look to the report completed by Marshall, Income Support and HIV/AIDS: The Experiences of Persons Living with HIV and AIDS in Nova Scotia which recommended that increasing the personal allowance rates to actually reflect the cost of food, to enable income assistance recipients to purchase a healthy nutritious diet.

Issue 7: Episodic Illness

Episodic illness or disability involves having periods of good health and periods of illness. The periods of illness are often unpredictable in occurrence and length. HIV is an example of episodic illness, but so are multiple sclerosis, lupus, arthritis, cancer, diabetes, and mental and mood disorders. Millions of Canadians are affected by at least one of these diseases in their lifetime.

Episodic illnesses are especially challenging because they are so unpredictable, making it difficult to set goals and work steadily. Flexible or part time work arrangements may not be an option, and health care and income support services are not well coordinated to offer appropriate assistance. However, people with episodic illnesses often must rely on federal or provincial government benefits or similar programs from private companies for income support (Canadian Working Group on HIV and Rehabilitation, 2009). The programs typically used are:

- Employment Insurance (EI) sickness benefits
- Long term disability (LTD) and extended health benefits (vision, dental, prescription drugs, physiotherapy, etc.) provided by employee group insurance plans
- Canadian Pension Plan Disability Program (CPP-D), and
- Provincial Disability and Social Assistance programs.

It is estimated that by 2024, over 80,000 Canadians with episodic illnesses will be receiving disability benefits (Stapleton & Tweddle, 2008).

Most of the income support programs mentioned above do not account for episodic illness, but use strict definitions which require a person to claim “able to work” or “fully disabled” (Stapleton & Tweddle, 2008). People with episodic illnesses can get trapped in poverty by having to withdraw from the workforce entirely and remain on income support, even during periods of good health. The person is not permitted to work, not even part time, when they are feeling well without losing all disability benefits, and must continue to prove they are ill each time they apply for disability payments. When the person loses disability benefits, they also lose health benefits such as prescription drugs, dental, physiotherapy, etc., which they may not get through their workplace, creating another barrier to returning to work. People with episodic illnesses are more likely to have poorer health because the stress over employment and income issues impacts their ability to cope with the illness. They are also subject to social exclusion if they are prevented from re-entering the workforce, which can have an impact on self-esteem, levels of social support, dignity, and overall health (Canadian Working Group on HIV and Rehabilitation, 2009; Stapleton & Tweddle, 2008).

PHAs interviewed by Marshall (2007) expressed the challenges they face remaining in the workforce due to the episodic nature of their illness. They were

often not provided with enough of an allowance to cover the costs of returning to the work force or going to school. As of 2007, the ESIA program in Nova Scotia did not provide assistance to recipients for educational programs more than two years long. Participants described program rules as “disincentives to work”, because it affects their drug coverage and disability entitlement, so “returning to work or an educational program is penalized.”

Issue 8: Navigating 'the System'

Navigating the healthcare system and social programs is a complex process; so much so, that it prevents many Canadians from accessing the services they need. PHAs on social assistance in Nova Scotia often have difficulty finding their way through the maze of health and social programs. Some of accessibility issues highlighted by participants Marshall's (2007) included: staff need to be reachable in person or by telephone; eligibility rules should be clear and in plain language; staff should be knowledgeable about the program and inform participants of which benefits they are entitled; and, staff should be respectful and understanding of the issues of living with HIV/AIDS. Based on these findings, the report recommended increased access to information and transparency about the ESIA program, including use of plain language and simplifying and streamlining procedures.

For some individuals, the system is almost entirely out of reach. For example, if a person does not have a permanent address, they are not entitled to a health card, and often have difficulties accessing regular health services. Their only contact with public support services may be food and shelter services, neither of which is equipped to help clients navigate systems such as ESIA, etc. A case worker may be asked to help, or feel responsible for helping their clients navigate the whole system, which is beyond their job description (Marshall, 2007). Case workers can become overburdened by these clients, because there is no other way they can access support from the system. Eventually, this places a burden on the entire system, and fewer clients are served.

If a person is a member of a marginalized population, difficulties with navigation may be exacerbated. For example, Sam dropped out of high school, so he may not have the literacy level to understand what services and/or benefits may be available, how they work together, how to access them and how to complete application forms (both paper-based and electronic). Many people are not aware of all of the benefits to which they may be entitled. The programs are complex and inter-related (across departments) and often one needs assistance to navigate them – to know to ask the right questions. The forms can be confusing and the language is not accessible.

We know that in the health system, patient navigators and cultural interpreters are becoming more common, but these services need to be expanded to other sectors, such as various pensions and income assistance programs, and job/education programs (Pyra Management Consulting Services Inc., 2005). According to a report written for the AIDS Coalition of Nova Scotia, a provincial HIV/AIDS Patient Navigation program would be a step toward delivering more effective client-centred services. Case managers in this proposed system would provide their clients with counselling, education, support and

assistance in navigating the complex provincial medical and social services. If the program were effective, it could be extended to anyone living with a chronic illness in Nova Scotia.

SECTION V: LEARNING MORE ABOUT VULNERABILITY & SOCIAL INCLUSION

There are a number of existing resources for learning more about issues of vulnerability and social inclusion, and how best to respond to or mitigate inequities. The following is a preliminary list of readings and other resources to explore these issues.

Readings

Bauer, G.; Hammond, R.; Kaay, M.; Tokawa, K.; K, A. and Boyce, M. (November 2009). Best Practices for Including Trans Participants in Research: Trans PULSE Project. OHTN Research Conference presentation.

Boyce, P. et al. (2007). Putting sexuality (back) into HIV/AIDS: Issues, theory and practice. Global Public Health, 2(1), pp.1-34.

CIHR Institute of Gender and Health. (2012). What a Difference Sex and Gender Make: A Gender, Sex and Health Research Casebook. Available online: www.cihr-irsc.gc.ca/e/44082.html

Evans, T and H. Brown (2003). Road traffic crashes: Operationalizing equity in the context of health sector reform. Injury Control and Safety Promotion, 10 (1-2), pp.11-12.

Hankivsky O. (2012) An Intersectionality-Based Policy Analysis Framework. Vancouver: Institute for Intersectionality Research and Policy, Simon Fraser University.

Health Canada. Gender Based Analysis. http://www.hc-sc.gc.ca/hl-vs/gender-genre/analys/gender-sexes-eng.php

Heidari, S. et al. (2012). Gender-sensitive reporting in medical research. Journal of the International AIDS Society, 15(11). Provisional copy, PNA.

Nowatzki, N. (2011). Sex is not enough: The Need for Gender-Based Analysis in Health Research. Health Care for Women International, 32, pp.263-277.

Clow, B., Pederson, A., Haworth-Brockman, M., & Bernier, J. (2009). *Rising to the Challenge: Sex- and gender-based analysis for health planning, policy and research in Canada*. Halifax, NS: Atlantic Centre of Excellence for Women's Health.

Online Resources - Checklists or Lens

An Inclusion Lens: Workbook for Social and Economic Inclusion and Exclusion. 2002
http://www.phac-aspc.gc.ca/canada/regions/atlantic/Publications/Inclusion_lens/

Bringing Gender and Diversity to Our Work
www.nationalframework-cadrenational.ca/images/uploads/SexDiversityChecklist.pdf

Gender Analysis for Project Planners. ICAD
www.icad-cisd.com/pdf/Gender_Analysis_for_Project_Planners_EN_FINAL.pdf

Intersectionality: Moving Women's Health Research and Policy Forward
http://www.bccewh.bc.ca/publications-resources/documents/IntersectionaliyMovingwomenshealthresearchandpolicyforward.pdf

Nova Scotia Community Development Policy
http://www.gov.ns.ca/econ/cdpolicy/policy.asp

Our Voices: First Nations, Metis and Inuit
http://www.aboriginalgba.ca/

Prairie Women's Health Centre of Excellence
www.pwhce.ca/hivaids/resources/GBA_checklist_and_background.pdf

Sex, Gender and Health Research Canadian Institutes of Health Research Guide: A Tool for CIHR Applicants. CIHR http://www.cihr-irsc.gc.ca/e/32019.html

SGBA e-learning Resource: Rising to the Challenge. http://sgba-resource.ca/en

Tool Kits

Engaging Communities : A Toolkit for Building Healthy and Resilient Communities. Berkana Institute and Neighbourhood Centre. Also available from the NS Advisory Commission on AIDS ; or see http://www.margaretwheatley.com/DVD-podcasts-more.html#other

Everyday Democracy: Ideas and Tools for Community Change. http://www.everyday-democracy.org/en/index.aspx

Workshops

For Nova Scotia government employees there are courses on respectful workplaces, culture competency and Aboriginal perspectives.

Personal or Experiential Ways of Learning

Consider:

- Undertaking deliberative dialogue interviews with people who work with vulnerable populations and/or who themselves come from a vulnerable population and can speak with a first voice.
- Spending a day job shadowing someone who works on the frontline in a community based service organization.
- Becoming a participant in an advisory committee for a community based project or organization.

Other resources include:

Thinking Together: The Power of Deliberative Dialogue.
http://www.scottlondon.com/reports/dialogue.html

Learning journeys whereby a small group spends some time with a community based service exploring the services and/or reality of the population group.
http://www.meadowlarkinstitute.org/about.asp

Community-based Participatory Research
http://en.wikipedia.org/wiki/Community-based_participatory_research

McIntyre, Alice. 2008. Participatory Action Research, Sage Publications Inc.

Participatory Action Research. http://en.wikipedia.org/wiki/Participatory_action_research

Learning Journey Rubric. http://mountmadonnaschool.org/values/learning-journey-rubric/

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Bernier, J., & McLellan, K. (2011). *Health status and health services use of female and male prisoners in provincial jail*. Halifax, NS: Atlantic Centre of Excellence for Women's Health.

Canadian AIDS Treatment Information Exchange. (2010). Managing your health: A guide for people living with HIV: Chapter 6: Your emotional health. Accessed from http://www.catie.ca/eng/myh/ch6.shtml#depression.

Canadian Working Group on HIV and Rehabilitation. (2010). *What is an episodic disability?* Accessed from http://www.hivandrehab.ca/EN/resources/description_episodic_disabilties.php

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