



# “RELATIONAL CARE”

**A Guide to Health Care and  
Support for Aboriginal People  
Living with HIV/AIDS**



**CANADIAN ABORIGINAL  
AIDS NETWORK**

FINAL REPORT  
**2008**



## **BRIEF OVERVIEW OF THE CANADIAN ABORIGINAL AIDS NETWORK (CAAN)**

- Established in 1997
- Represents over 400 member organizations and individuals
- Governed by a national 13-member Board of Directors
- Has a four-member Executive Board of Directors
- Provides a national forum for members to express needs and concerns
- Ensures access to HIV/AIDS-related services through advocacy
- Provides relevant, accurate and up-to-date HIV/AIDS information

## **MISSION STATEMENT**

As a key national voice of a collection of individuals, organizations and provincial/territorial associations, CAAN provides leadership, support and advocacy for Aboriginal people living with and affected by Human Immunodeficiency Virus/Acquired Immune Deficiency Syndrome (HIV/AIDS). CAAN faces the challenges created by HIV/AIDS in a spirit of wholeness and healing that promotes empowerment and inclusion, and honours the cultural traditions, uniqueness and diversity of all First Nations, Inuit and Métis people, regardless of where they reside.

## **ACKNOWLEDGEMENTS**

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CAAN also thanks the research team and members of the National Research Advisory Committee (NRAC).

## **IN MEMORIAM**

The research team, together with the board and staff of CAAN, want to acknowledge the crossing over of three of our brothers and sisters who, in their own way, helped CAAN understand what many Aboriginal People Living with HIV/AIDS (APHAs) experience as they journey through this life. Jocelyn, Gerard (Gerry) and Thomas (Tommy) touched our lives, spoke strong words for those who had no voice, and helped us laugh and cry with them as they shared their lives with us in this study. With each passing, we are reminded that this battle is not over . . . yet. We honour their memory by keeping the fire burning.

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**Canadian Aboriginal AIDS Network** ©

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## PREFACE

*Early one morning a tiny bird came knocking at my window. Not fully awake yet, it took me awhile to determine what the noise was, and then walk toward where the sound was coming from. There on the window ledge was the tiny bird. I tried to shoo it away, but it would not leave. I told a friend about the bird knocking at my window and said I felt that someone was about to pass. A little time later, this same person came to me and said he, too, had had the visitor. A bird also knocked on his window. I said “it must be someone we both know.” A bit more time passed and then my brother said he got a call from someone who asked him what it means when a bird knocks on your window. I asked my father and he agreed — that someone was about to pass. Three times the visitor made sure I knew or got the message. Not long after, a friend called and said his mother had been told she had cancer. I went to visit. I began to visit her almost every weekend, a six-hour drive. Without realizing it, what began to unfold was a need, spiritual in nature, and I soon realized it was her spirit who reached out for help and came in the form of a messenger — the bird who knocked on my window. My friend’s mother passed within months, but not before opening my eyes again to how we are surrounded by life, all life — our relatives. I was the one who happened to be open to her call for help. I was there when she crossed over, and I know for certain that we are all related.*

**Black Bear Standing Looking For Medicine**

Whether you believe this story or not is unimportant. What is important is that the person telling it believes it. It is with this in mind that this study — which speaks to Aboriginal People Living with HIV/AIDS and service providers — is written. This research, and the stories of those who trusted us enough to share their experiences, is about helping both Aboriginal and non-Aboriginal people understand a different world view.

We recognize the unique cultural differences and similarities of those who were here first in North America (Turtle Island), including those of mixed heritage after European contact. One concept is shared: we are all related. People come into our lives for a reason, whether for a short time or for longer periods. This interconnectedness, found in the phrase “all my relations,” speaks to our connection to the land, the water, the air, and what we see and cannot see. It speaks to our understanding of the plants and medicines we gather, and to how we approach animal life when we need food and shelter. It speaks to the winged ones who carry messages for us.

We hope this study will open the eyes of service providers to not see just an Aboriginal person sitting in front of them, but someone on a journey, someone with a heritage that goes back generations, even when they may not seem to be aware of it. How we connect with each person is what we talk about in this report.

**Kevin Barlow, CEO - CAAN and Co-Principal Investigator**

# EXECUTIVE SUMMARY

## INTRODUCING “RELATIONAL CARE”

- This study began as an investigation into the need for culturally competent care for Aboriginal People Living with HIV/AIDS (APHAs) in Canada. It resulted in an understanding of the need for what we term “relational care.” The root of relational care is connection, the link between all living things that in some Aboriginal philosophies is captured in the phrase “all my relations.” Relational care is an interactive, caring, respectful path for culturally competent services leading to the well-being of the whole person. Imagine if a Doctor or nurse took time to acknowledge that the person they are treating came across their path for a reason, some deeper purpose, such as to teach or learn from one another? As with the messenger on the preceding page, it is a tremendous responsibility and perhaps gift, to be a part of someone’s passing into the spirit world. And until they pass, being of service to assist in finding a healthier way to live also carries that same responsibility.
- While most cultural concepts of care (e.g., cultural competence, cultural safety) call attention to relationships of trust, relational care embraces the entire relationship between caregiver and care recipient. Relational care encompasses the physical, social, emotional and spiritual dimensions of human connection. Healthy care relationships are critical because unhealthy relationships often result in Aboriginal people discontinuing care.
- The concept of relational care is rooted in values and teachings of Inuit, Métis and First Nations cultures. These values and teachings provide pathways for our analysis of the experiences of APHAs in accessing care, treatment and support, and frame our analysis of relational care service provision. In this report we outline Seven Sacred Teachings which are found in many First Nations to elicit care relationships that foster positive health outcomes for APHAs. We acknowledge that the Inuit and Métis also have their own belief systems which may be similar to these.

## STUDY METHODOLOGY

- This was a three-year qualitative research study (2005–2008) involving five target regions in Canada: Atlantic, Quebec, Ontario, Manitoba, and Saskatchewan. The study set out to meet three research objectives:
  - To explore the perceptions of cultural concepts of care among APHAs and HIV/AIDS health care providers;
  - To document the lived experiences of APHAs regarding culturally competent or incompetent health care; and
  - To design a wise practices guide for HIV/AIDS health care providers who work with APHAs.



- Data collection was conducted in two phases. Phase 1 consisted of interviews with APHAs. In Phase 2 we returned to each region where APHA participants accessed services, and conducted focus group and interview sessions with primary and community-based HIV/AIDS professionals:
  - Thirty-five APHAs participated in semi-structured interviews. Within this group, 22 identified as First Nations, such as Mik'maq, Maliseet, Innu, Cree, Ojibway and Oji-Cree cultures represented. There were eight Métis participants, most of whom lived in western Canada. The remaining five persons living with HIV/AIDS (PHA) participants were Inuit, each of whom left Nunavut or Nunavik who had moved to southern urban centres, mainly in central Canada.
  - Fifty-two HIV/AIDS service providers, representing 25 organizations, participated in focus groups and interviews. The service provider sample included both primary (medical) and community-based (support) health professionals who work at various types of agencies such as AIDS Service Organizations (ASOs, both mainstream and Aboriginal-specific), HIV clinics, community health centres, Native Friendship Centres, addiction treatment centres, youth agencies and HIV housing agencies.
- Taken as a whole, the knowledge of both APHAs and health care providers in this study represent a broad range of individual and organizational experiences in both accessing and providing care, treatment and support for HIV/AIDS. Their knowledge of Aboriginal cultural issues and health care systems in various regions across Canada provides a rich source of information toward building a meaningful and competent approach to care for Aboriginal people living with HIV/AIDS.

## **THE APHA EXPERIENCE: BEING ABORIGINAL, BEING POSITIVE**

- Living with HIV/AIDS is often described by APHAs as an emotionally difficult journey that begins immediately after testing positive for HIV. Many APHAs described HIV discovery as a devastating experience and a sudden loss of hope for the future. For some APHAs, the crisis of HIV was a wake-up call to change their lifestyles. Whatever the initial reaction to discovering their positive HIV status, participants described how pathways to healing can be facilitated by health care and support that nurtures not only physical health but also emotional and mental stability — and for some, cultural and spiritual renewal.
- Service providers generally recognized that APHAs express healing in more holistic terms, where physical, spiritual, emotional and mental wellness intersect. Many medical and support professionals made it clear that living with HIV/AIDS is a lifelong journey, and that many PHAs struggle to deal with a complexity of lifestyle and health issues that led to their HIV infection in the first place. While the journey itself is not Aboriginal-specific, service providers generally agreed that there are cultural components to how APHAs balance positive and negative experiences and how they respond to diagnosis, adhere to treatment, access support, overcome obstacles and learn to live with HIV/AIDS.

- Relational care begins with a common understanding of past relationships between Aboriginal peoples and European colonizers. Those engaged in relational care acknowledge the historic trauma of past colonial relationships on the health of Aboriginal peoples in Canada and work with clients to minimize further harm:
  - “Historic trauma” associated with centuries of colonization of Indigenous peoples of the Americas is commonly cited as a main factor in the health disparities experienced by Aboriginal peoples in Canada. Researchers commonly consider rapidly increasing rates of HIV and hepatitis C virus (HCV) infection among Aboriginal youth as a reflection of the complex effects of addiction, social dislocation, discrimination, human rights violation and poverty.
  - Approximately half of the APHA participants shared their sense of disconnection from Aboriginal culture for various reasons. For some, this sense of disconnection was due to adoption or fostering by non-Aboriginal families. Several APHAs traced their disconnection to attendance at residential schools or to recent reinstatement of their First Nations status through Bill C-31. For others, traumatic experiences involving HIV stigma, homophobia, ostracism or abusive relationships have caused rifts between them and their families or home communities. Several APHAs left their home communities because of its isolation or lack of services and other opportunities. Many APHAs concluded that returning home to their communities of origin was no longer an option.
- An HIV diagnosis can shatter the meaning people hold about life and their place in the world. Often APHAs described how testing positive for HIV resulted in overwhelming fear that illness would quickly lead to crippling illness and/or sudden death. For some of these individuals, coping meant withdrawing from social and family supports. Frequently, APHAs’ lives entered a period of intensified negative coping based on past street involvement and substance abuse, often reflecting high-risk behaviours that led to the diagnosis.
- For most people diagnosed with HIV/AIDS, the shame and failure associated with experiences of stigma and homophobia further complicate HIV discovery. These factors also represent recognized barriers to disclosure and to accessing treatment and support services. Service providers say that HIV stigma and racial prejudice tend to limit APHAs’ access to medical and support services, both inside and outside Aboriginal communities:
  - From within home communities, HIV stigma and homophobic attitudes limit access to services by APHAs who are concerned about privacy and confidentiality. From a medical services point of view, HIV stigma in Aboriginal communities discourages HIV testing and threatens to isolate APHAs from important family support networks. Service providers frequently commented on the burden being placed on APHAs’ sense of Aboriginal identity due to homophobic attitudes and associated fears about HIV/AIDS. This is a serious concern for APHAs, who have been judged by and are now unwelcome in their home communities.

- From outside, attitudinal obstacles in the paths of APHAs' healing journeys include perceptions of discriminatory practices by social assistance agencies, pharmacists, clinicians and other mainstream service agencies. Racist attitudes toward Aboriginal peoples from within health care and support environments add another layer of stress to an already difficult situation. APHAs' perceptions of prejudice were often woven into and associated with stories of racism, HIV stigma and/or homophobia.
- APHAs who related experiences of perceived racism did so almost exclusively within the context of primary medical services. In particular, there was a perception that health care professionals associated Aboriginal identity with addictive behaviour. Racist attitudes were also perceived in terms of dominance of the western biomedical model of health care over alternative, complementary or traditional wellness practices.
- APHAs with overlapping identities — being Aboriginal, being HIV-positive, being gay, being an addict, being a sex worker — described pulling away from familial and medical relationships in an effort to protect against painful experiences of stigma, racism or homophobia.
- For some APHAs, testing positive was a turning point in their lives, leading to a “good journey” or “better path.” More than one-third of the APHAs interviewed talked about reconnecting with their Aboriginal heritage since testing as HIV-positive. Culture was seen as a path toward new meaning in life, learning to take pride in being Aboriginal and generally improving self-esteem. Other APHAs did not seek cultural or traditional avenues but nevertheless viewed HIV as an opportunity to grow. In this sense, HIV was seen as a “gift” that triggered reflection, introspection and re-evaluation of life and health priorities.
- Following an HIV-positive or AIDS diagnosis, human connectedness and a sense of belonging have proven to be crucial elements in learning to cope and live with HIV/AIDS. APHAs often described this human connectedness as “second family.” Strategies included volunteering at HIV drop-ins and Native Friendship Centres; joining support groups such as talking circles; becoming active members of local, regional, and national Aboriginal AIDS organizations; learning speaking skills in order to inform Aboriginal students about the risks of HIV/AIDS; and accepting help from others, especially family and friends.
- Among those APHAs who were seeking to reconnect with their cultural heritage, exploring traditional Aboriginal approaches to wellness was an important pathway. Health care and support professionals generally agreed that traditional wellness approaches promoted positive health outcomes. Relational care in this instance required that the health care provider be willing to have a conversation with their Aboriginal patient about how to integrate western medical treatments and traditional wellness practices.

## RELATIONAL CARE: PROMOTING HEALING

- APHAs described relational care as involving two main themes — connecting and relationships:
  - Connecting refers to APHAs' perception that a safe environment is one in which they felt comfortable, important and cared for as a person, not a disease.
  - Relationships were conceptualized as the ways in which service providers interacted with APHAs, and how they negotiated the care, treatment and support appropriate to each situation. Good care relationships reflected the Seven Sacred Teachings: love, respect, courage, honesty, wisdom, humility and truth.
- Service providers emphasized that competency had many more components than just provision of culturally relevant skills and knowledge. Core elements of relational care include trust; rapport; respect for individuality; regard for Aboriginal and holistic approaches to wellbeing; flexibility and openness toward alternative, complementary and integrated care strategies; and willingness to relinquish expert status and learn about how better to meet the needs of Aboriginal PHAs.
- In connecting with health care and support, APHAs revealed ways in which they could relate to physical, social, emotional and spiritual environments. Similarly, service providers shared their observations and experiences about how, when and why they were able to connect with their Aboriginal clients:
  - Physical connection was described as a sense of space and place where APHAs felt welcomed, comfortable, relaxed and safe. In their descriptions of “ideal care,” many APHAs described physical spaces that felt “like home” and that acknowledged the local Aboriginal culture in its art or architecture. Trust in the level of confidentiality within this environment was imperative.
  - Social connection was recognized as a familiar face, a shared experience, a friend who was not an authority, and knowledge that an APHA is not alone. An Aboriginal presence (e.g., staff) was seen as more welcoming and had the potential to enhance the responsiveness of some clients to the environment, resulting in improved access to care. In other cases, service providers who were themselves HIV-positive were viewed as the foundation upon which some APHAs felt they could best relate.
  - Listening, sharing and sense of family were described as ingredients of emotional connection. Inasmuch as an Aboriginal presence within care environments was viewed as favourable by almost all APHA participants, creating and providing a safe emotional space was equally important. A common theme in APHAs' stories about the drop-ins, community health centres, or Native Friendship Centres they frequented was the strong emotional connection they had with HIV-positive peers who were like “family.”

- Spiritual connection embraced notions of acceptance, open-mindedness and human competence. It celebrated diversity of race, gender, sexuality and HIV status. This meant acknowledging the diversity of the APHA population in terms of cultural background, personal experience and sexual orientation. APHAs objected to being stereotyped, and advocated equal treatment for all, regardless of culture. Fundamental to making a spiritual connection were service providers characterized as understanding, open-minded and dynamic.
- Personable relationships were critical to APHA participants' perceptions of culturally competent and safe care. In particular, having a one-on-one and dependable relationship with service providers, whether they were Aboriginal or non-Aboriginal, was often reported as the most important component of care. APHAs talked about how meaningful interactions and affirmative social encounters shaped their experience with health care facilities and service organizations.
- For virtually all of the APHAs we spoke with, being able to trust a service provider was the dividing line between good and bad care. There was overwhelming agreement among service provider participants that building rapport with Aboriginal clients takes longer than with non-Aboriginal clients. There was an initial mistrust by APHAs of health and social service organizations, and apprehension about being judged by those in authority. Trust was defined by both APHAs and service providers to include non-judgmental attitudes and behaviours; knowledge and capacity to understand issues around HIV/AIDS; sexual orientation, or addictions; and comprehension of confidentiality and anonymity concerns.
- A number of APHAs were explicit about the importance of a holistic approach. They sought it out and were critical of care providers who were closed to approaches that go beyond physical or medical care. Service providers who acknowledge and help APHAs address emotional, mental, social and physical needs, and engage in relational care by encouraging APHAs to access a range of care and support for their whole well-being.
- Relational care reflects a willingness on the part of service providers to regard individual differences by offering care options to APHAs, and the courage to respect APHAs priorities and support their decisions. At the same time, relational care providers seek to balance sometimes contradictory needs, and to administer wisdom in helping APHAs to integrate types of care, such as Aboriginal traditional with western medical practices, or HIV and addiction treatments.
- Relational care suggests that service providers are not always the experts. It demands a willingness and desire to learn about the contexts within which APHAs seek support or care. Relational care providers make it their business to understand Aboriginal clients' histories of trauma, social, economic and logistical matters that affect how and where appropriate care can be found, as well as resources to fulfil information and referral service requests:

- Service providers recommended both immediate and long-term cultural resources. Immediate resources include information and clarification about access to services by off/on-reserve and Status/Non-Status Aboriginal clients; centralized access to Aboriginal resources; and HIV/AIDS resources that are culturally appropriate at a local/regional level. Long-term recommendations include community partnerships with Aboriginal organizations such as Aboriginal ASOs and Native Friendship Centres, outreach and mobilized services, and integrated addiction and infectious disease services.

## WISE PRACTICES FOR PROVIDING RELATIONAL CARE

- *A legacy* — Acknowledge that many Aboriginal people wear the legacy of colonialism, including historical trauma impacts to varying degrees. Observe those who may more noticeably experience multiple challenges as a result of this legacy.
- *Cultural connection and disconnection* — Approach Aboriginal families as a unit. Increasingly, several generations within a single extended family are infected with HIV. In Aboriginal communities — urban or rural — it is not enough to provide education and information at an individual level; make the information available to everyone.
- *Living with HIV/AIDS in Aboriginal communities* — Health practitioners, chiefs, mayors, council members, elected and non-elected leaders, Elders and community members who want to create a safe environment and provide relational care should deliver a deliberate and sustained message normalizing HIV/AIDS to Aboriginal families and communities. Don't wait for HIV to infect a community, or ostracize someone with HIV or AIDS to solve the problem.
- *Racism and perceived racism* — Be acutely aware that many Aboriginal people have experienced racism and discrimination and do not presume that substance abuse is a factor in their lives. Make every effort to reduce the perception that because they are Aboriginal, substance abuse or social assistance is presumed to be part of their life. Recognize that each Aboriginal client comes from a unique background, and treat each client as an individual who has the capacity and right to make their own informed health choices.
- *Overcoming barriers* — Treat the person and not the disease. Be willing to find ways to help APHAs overcome lifestyle and health barriers (e.g., integrate addiction treatment and HIV care). Encourage patients' participation in decision-making and honour APHAs' health choices.
- *The catalyst and culture* — Maintain a close working knowledge of Aboriginal-specific services in order to help APHAs who consider their HIV-positive diagnosis as a catalyst toward seeking a better path in life and health, particularly through reconnecting with their Aboriginal identity and culture. For referrals, contact knowledgeable Elders and Aboriginal organizations that provide discreet interaction and protect confidentiality.

- *Second family* — Create a safe space for APHAs to connect and support one another, one where they are assured of confidentiality and a non-judgmental atmosphere. Show understanding, and help APHAs who cannot be with their families of origin to find a “second family” that they can belong to who will walk with them on their healing journey.
- *Making care connections* — Take practical steps in care provision (e.g., allow a space within a facility where traditional Aboriginal wellness practices and ceremonies can take place). Work with Aboriginal agencies that have Elder services so that support can be obtained when needed. Acknowledge that many Aboriginal facilities are situated in poorer neighbourhoods yet fill an important role in the social fabric of the community.
- *Negotiating care relationship* — Express a genuine respect and trust for Aboriginal clients in providing care. Respect for the resilient nature of individuals, even when it’s not obvious, is vital and the foundation of relational care.
- *Cultural resources* — Aboriginal ASOs require long-term funding to provide mainstream service agencies and HIV clinics with cultural resources appropriate to their regions. Organizations should fund and accommodate access to Aboriginal, HIV/AIDS and educational resources. Staff should be flexible, develop new programs, and get to know their clients, communities, Aboriginal referral contacts and partners.





# 1. INTRODUCTION

We began with a study to investigate the need for culturally competent care for Aboriginal people living with HIV/AIDS (APHAs) in Canada. We ended with an understanding of the need for relational care. “Relational care” is health care centred on Aboriginal cultural concepts of caring for and meeting the needs of Aboriginal people living with HIV and AIDS. It is rooted in connections within and relationships among Aboriginal people and health care providers; it is nourished by indigenous teachings and values; and it acknowledges the present-day impact of the profoundly damaging history of European colonization. Fundamentally, relational care is an interactive, caring, respectful path for culturally competent services leading to the well-being of the whole person.

The impetus for this study on Aboriginal cultural concepts of care emerged from a series of consultations between the Canadian Aboriginal AIDS Network (CAAN) and members of the Aboriginal HIV/AIDS community. In particular, the findings of CAAN’s national survey on care, treatment and support issues for APHAs pointed to the need to more aggressively attend to issues of cultural content and process in HIV/AIDS health programming.<sup>1</sup> That survey also made it clear that while Aboriginal cultures in Canada are diverse and distinct, there exist barriers that are commonly experienced by HIV-positive Aboriginal persons. This commonality provides the underlying rationale for exploring and addressing cultural issues of care, treatment and support for APHAs.

HIV/AIDS continues to be a serious health concern for all Aboriginal communities. The number of new HIV infections among Aboriginal peoples continues to grow at a time when new infections are levelling off in the non-Aboriginal population. In 2006, the proportion of positive HIV test reports attributed to Aboriginal persons was 27.3% among provinces and territories reporting ethnicity information.<sup>2</sup> The number of AIDS diagnoses among Aboriginal groups in Canada (where ethnicity is reported) has increased from 1.6% prior to 1995 to 24.4% in 2006. Injecting drug use has risen dramatically as the main transmission mode for HIV in Canada’s Aboriginal population.<sup>3</sup> Among Aboriginal peoples, the rise in HIV rates is most apparent in Canada’s inner cities, where an increasing proportion now lives. While HIV/AIDS is still not a curable disease, new knowledge and medications allow some people to better manage their illness. This means a significant change from end-of-life issues to healthy-living issues and translates into an increased duration and altered nature of the patient–provider relationship.<sup>4</sup>

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1 Jackson and Reimer 2008.

2 In 2006, ethnicity data was available for 35.5% of AIDS cases and 29.2% of positive HIV tests. Ethnicity data is not available from Quebec and Ontario (PHAC 2007).

3 Of reported AIDS cases with known exposure, the proportion of Aboriginal cases attributed to injecting drug use has dramatically increased over time, from 18.0% before 1995 to 47.2% during 1995–2000 and 50.3% during 2001–2006. A review of positive HIV test reports with exposure category information between 1998 and 2006 indicates that injecting drug use was the most common identified route of transmission, at 58.8%, among Aboriginal persons (PHAC 2007).

4 Cain and Todd 2002.

Prolonged patient–provider relationships have significant repercussions for the present study. Over the past decade, Aboriginal health organizations, as well as practitioners and researchers working in the field of Aboriginal health in Canada, have consistently advocated for increased cultural content in health services and programming.<sup>5</sup> Unfortunately, current examples of discrimination against Aboriginal peoples and APHAs by health care service providers indicate that many health professionals still do not have the cross-cultural learning that is required for culturally competent health care.<sup>6</sup> As Aboriginal peoples comprise an ever increasing percentage of the HIV/AIDS case load, and as the duration of the patient–provider relationship is expected to lengthen while APHAs learn to manage their illness, it is increasingly important for health professionals to be familiar with and competent in the cultural contexts of their Aboriginal clients.

## 1.1 CULTURAL CONCEPTS OF CARE: THE LITERATURE

The call for greater attention to cultural factors in care, treatment and support for APHAs is reflected in the current Canadian and international literature. Cultural issues in the specific health care context of HIV/AIDS are topics of particular concern with regard to Aboriginal populations in Canada<sup>7</sup>, and more so in relation to American Indians, Alaskan Natives and Native Hawaiians in the United States.<sup>8</sup> Cultural concepts of care have evolved to adapt to various health care settings and to meet different needs in multicultural societies in Canada, the United States, Australia, New Zealand and Britain. Much of the recent attention to developing effective cultural concepts of care is occurring within the context of health and wellness for indigenous peoples.

When originally conceived in the 1980s, cultural competence shifted from a passive model of cultural sensitivity to various client cultures to an action-oriented model of developing skills among health care providers that would allow them to function effectively in a cultural context other than their own.<sup>9</sup> *Cultural competence* is generally defined as the acquisition and maintenance of a set of skills — including behaviours, attitudes and policies — for the delivery of appropriate care in a multi-cultural context.<sup>10</sup> Campinha-Bacote provides a model that consists of the following five interdependent constructs: cultural awareness, cultural knowledge, cultural skill, cultural encounters and cultural desire. While each of these constructs is important in its own right, it is cultural desire that provides the impetus for the journey from

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5 Aboriginal Nurses Association of Canada 1996; Browne et al. 2000; Browne and Fiske 2001; Dokis 2002; Gray 1996; Hoskins 1999; Kue Young et al. 2003; Malcolm et al. 2003; NAHO 2006; Purden 2005; Racher and Annis 2007; RCAP 1996; Smye and Browne 2002; Smylie 2001; Tookenay 1996; Warry 2000.

6 CAAN 2004; Jackson 2003 ; Matiation 1999.

7 Bucharski et al. 2006; Schilder et al. 1998, 2001.

8 Aguilera and Plasencia 2005; Foley et al. 2005; Gilley 2006; Gilley and Co-CKé 2005; Hamill and Dickey 2005; Ka'opua and Mueller 2004; Nebelkopf and Penagos 2005; Speier 2005.

9 Chin 2000; Kleinman 1980; Kleinman and Good 1985.

10 Gray and McPherson 2005; Hamill and Dickey 2005; Ka'opua and Mueller 2004; NAHO 2006; Schilder et al. 1998, 2001.

cultural incompetence by stimulating health care providers to seek cultural encounters, build cultural knowledge, conduct culturally sensitive assessments, and be humble to the process of cultural awareness.<sup>11</sup>

More recently, health researchers and educators have been critical of “content” models of competence that emphasize knowledge of cultural facts and that can inadvertently create or reinforce stereotypes. The notion of cultural competence has been reformulated as a process model of lifelong learning that can be applied to individual as well as institutional or system levels of care.<sup>12</sup> Purden adds that community collaboration is imperative to this process, citing, for example, programs at the Churchill Health Centre (Manitoba) where “traditional practices are respected and interwoven with conventional care as a result of collaborations between local health care professionals and members of Aboriginal associations.”<sup>13</sup>

In the bi-cultural context of Maori (marginal) vs. non-Maori (dominant) health care in New Zealand, nursing professionals and researchers have characterized cultural competency as *cultural safety*, a concept that recognizes the historical relationship of power between the health care provider and the patient. Cultural safety emphasizes relationships of trust in which the patient determines whether the care is “safe.”<sup>14</sup> In the Australian context, cultural safety is defined specifically for practitioners, emphasizing “an environment which is safe for people, where there is no assault, challenge or denial of their identity, of who they are and what they need,” concluding that “a lack of culturally safe health services place people from minorities at risk, especially Indigenous people, by dramatically reducing access to services.”<sup>15</sup> In the Canadian context, notions of cultural safety are applied to examine the power imbalances that characterize relationships between Aboriginal patients and their health care providers.<sup>16</sup> In a study of HIV-positive Aboriginal women in Alberta, cultural safety is key to addressing “broader systemic barriers” or “lack of trust” resulting from the colonization experience, institutionalized discrimination and child welfare involvement.<sup>17</sup>

The concept of *cultural humility* — advocated predominantly by health researchers in the United States<sup>18</sup> — incorporates a lifelong commitment on the part of health professionals to self-evaluation and self-critique in order to redress the power imbalances in the patient–physician dynamic. The goal is to develop mutually beneficial and non-paternalistic clinical and advocacy partnerships with communities on behalf of individuals and defined populations.

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11 Campinha-Bacote 2002.

12 Goode 2004; Purden 2005; Racher and Annis 2007; Whaley and Davis 2007.

13 Purden 2005:229.

14 Gray and McPherson 2005; Papps and Ramsden 1996; Phillips 2005; Polaschek 1998; Ramsden 2002; Richardson 2004; Wepa 2001; cf. NAHO 2006.

15 Bourke et al. 2004:183.

16 Browne et al. 2000; Browne and Fiske 2001.

17 Bucharski et al. 2006:732, 741.

18 Juarez et al. 2006; Tervalon and Murray-García 1998.

Canadian researchers have referred to this self-reflective process as *cultural attunement*.<sup>19</sup> In the context of Aboriginal health in Canada, Hoskins characterizes cultural attunement with words like “harmony,” “cooperation” and “accord,” which signify “synchronicity” rather than expert positioning: to attune oneself means to walk beside or with another. Key to the concept of cultural attunement is acts of humility: those who are part of the dominant culture have to constrain their own inclination to constantly privilege their own perspective. As well, cultural attunement is characterized by reverence: a relationship in which the client is “revered” or “honoured.” Reverence — noted as “a highly regarded way of being in some cultures such as First Nations communities” — requires a person to think, act and listen from the heart.<sup>20</sup> Racher and Annis define “cultural attunement” as “a way of being, in relation to the other” and as part of a *cultural competence continuum* that includes acts of humility, self-exploration and building trust relationships, as well as “mutuality” — seeking common ground and emphasizing shared humanity. In the Aboriginal health context, these authors insist that “aspects of Canadian history such as residential schools must be acknowledged in order for people to be able to take responsibility for their contributions, seek to grow from them, and change oppressive tendencies. Recognizing that privilege is constantly operating to some degree and creating situations of power imbalance ... [it] is crucial in honest communication that builds trust and respect.”<sup>21</sup>

The idea of being culturally attuned is consistent with ideas of cultural responsiveness that describe health provision that “acknowledges clients’ cultural identities and take their beliefs, norms and values into account in the interventions.” In implementing a more practical concept of care at an inner-city primary health clinic to integrate HIV/mental health programming serving minority populations in New York City, culturally responsive health providers who are “empathic, culturally attuned and knowledgeable in HIV care” are effective in motivating HIV patients for self-improvement.<sup>22</sup> Notions of cultural attunement and cultural responsiveness tend to be preferred by health researchers and educators who consider cultural competence an unrealizable ideal.<sup>23</sup>

The cultural concepts of care discussed above are directed at health care service providers and institutions operating within a mainstream or dominant cultural system. The common demand is for health education and service models to attend to cultural factors of care that may improve health outcomes for members of minority groups, including APHAs. On rare occasion, anthropologists and indigenous researchers are turning their gaze to the dynamic role played by the minority community on that cultural care continuum. In the United States, for example, Gilley and Hawk Co’Cké use *cultural investment* to describe the sense of ownership

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19 Hoskins 1999; Racher and Annis 2007.

20 Hoskins 1999:79–82.

21 Racher and Annis 2007:264; cf. Goode 2004.

22 Winiarski et al. 2005:754.

23 Racher and Annis 2007; Winiarski et al. 2005.

a “two-spirit”<sup>24</sup> individual feels in the success and continuation of a particular social group or community. The concept of cultural investment focuses on the Aboriginal self, situating HIV-positive individuals in the learning and self-reflection processes required by specific traditional cultural and healing practices. Regional support groups for gay American Indians provide opportunities for cultural investment in social practices that most of the men feel are not available to them due to homophobia within their tribal and ceremonial communities. These opportunities also address issues around Native male HIV infection by encouraging cultural investment in Native social practices versus the sometimes bar scene-based culture of the gay community.<sup>25</sup>

Gilley also advocates for *cultural integration*, a concept that focuses on the role of the Aboriginal community. Instead of simply translating HIV/AIDS programming into Native culture, HIV prevention strategies must be de-colonized and integrated by Native peoples into their own disease theories and contemporary culture.<sup>26</sup>

## 1.2 “RELATIONAL CARE”: THE ABORIGINAL PERSPECTIVE

The concept of “relational care,” which emerged from the stories of participants in this study, emphasizes ideals relevant to Aboriginal peoples in Canada. Published descriptions of cultural concepts of care imply interactions between health care providers who belong to a dominant cultural group and clients/patients who do not. Although concepts of cultural competence, safety, humility and attunement improve on previous notions of cultural sensitivity, they are not framed specifically from the viewpoint and needs of Indigenous peoples. While most cultural concepts of care call attention to relationships of trust, relational care embraces the entire relationship between caregiver and recipient.

The root of relational care is *connection*, which, according to most Indigenous philosophies, is the fundamental principle upon which relationships are established and maintained. Connection is the essential link between all living and non-living things. Indeed, a deeper understanding of life among most, if not all, Indigenous peoples includes spirit, and goes beyond what some might view as inanimate objects that are “not” living. For example, a stone used in a sweat lodge is often called a “grandfather” and is considered to have a spirit, which contributes to the ceremony. Yet, the connection between human beings is a special and unique one in the sense that we share both physical and social space. Healthy relationships are based on mutual respect, humility, honesty and trust. The health of relationships between caregivers and recipients is especially critical given that unhealthy relationships often result in Aboriginal people discontinuing care.

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24 Two-spirited is often used to refer to Aboriginal people who identify themselves as gay, lesbian, bisexual or transgender (Matiation, 1999b, p.7), because it is “...more culturally relevant to Aboriginal lesbians and gay men [and recognizes] the traditions and sacredness of [a] people who maintain a balance by housing both the male and female spirit...” (Deschamps, 1998 n.d., p. 10).

25 Gilley and Co-Cké 2005:294–295.

26 Gilley 2006:561.

Relational care begins with a common understanding of past relationships between Aboriginal peoples and European colonizers. Those engaged in relational care acknowledge the historic trauma of past colonial relationships on the health of Aboriginal peoples in Canada, and work with clients to minimize further harm. Relational care encompasses the physical, social, emotional, spiritual and social dimensions of human connection. Health care providers demonstrate relational care when they create these types of connections with APHAs. Physical connection is established through a warm environment, a gentle hand of comfort, and kindness expressed in our eyes and our faces. Social connection begins when we acknowledge the place we occupy in the physical world and the power or privilege we might be given because of our race, gender, language or sexuality. It is made and nurtured when we set aside human constructions of power and work toward a common goal of wellness for Aboriginal peoples who are infected with or affected by HIV/AIDS. Emotional connection is made through listening, sharing and truly caring for the well-being of another human being, as we might our own family. Finally, spiritual connection can be achieved only through an understanding of the metaphysical space we all share — a space where race, gender and sexuality have no meaning.

The concept of relational care is rooted in values and teachings of Inuit, Métis and First Nations cultures. Traditional Inuit values are framed by the central theme of survival. The “Inuit way” values equality and consensus; flexibility and cooperation; peace and patience; individual freedom in a context of social responsibility, industriousness and innovation; respect (especially for Elders); family loyalty; sharing; and non-interference.<sup>27</sup> Métis values are shaped and honed by historical themes of coexistence, cultural adaptation, accommodation, diversity of experience, traditional syncretistic spirituality that blends Aboriginal and Christian teachings, and resistance against coercive power and societal stereotypes.<sup>28</sup>

Many First Nations cultures share values based on the Seven Sacred Teachings comprising love, respect, courage, honesty, wisdom, humility and truth.<sup>29</sup> These indigenous values and teachings provided pathways for our analysis of the experiences of Aboriginal people living with HIV/AIDS in accessing care, treatment and support in Canada.

Inuit, Métis and First Nations values and teachings also frame our analysis of relational care service provision. In this report we apply the Seven Sacred Teachings to elicit the connections and relationships between care professionals and APHAs that are important to positive health outcomes. Within the context of HIV and AIDS care, these sacred teachings express dimensions of relational care as:

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<sup>27</sup> Pauktuutit 1991.

<sup>28</sup> Barkwell et al. 2000.

<sup>29</sup> See, for example: [www.theturtlelodge.com/teachings.htm](http://www.theturtlelodge.com/teachings.htm) (accessed 23/06/2008).

- Love** Developing a caring relationship in which the life of each Aboriginal person is more important than the illness with which they are afflicted.
- Respect** Nurturing a positive regard for each Aboriginal person's feelings, thoughts, opinions, knowledge, diverse experiences and abilities.
- Courage** Engaging in an authentic relationship with each Aboriginal person whose life you are trying to benefit — in the face of potential scorn and ridicule by colleagues and the health care profession.
- Honesty** Earning the trust of each Aboriginal person for whom you are caring. Like respect, trust is earned through consistent integrity in what you say and do.
- Wisdom** Demonstrating that understanding is the root of wisdom. To understand, you must listen more than you speak.
- Humility** Offering care as a gift for which we feel honoured — and never in arrogance — and understanding that we are all helpless, angry or confused at times.
- Truth** Consistently seeking truth, even though it is seldom found — not just the truth of each Aboriginal person's situation, but the truth of our own privilege and power.

## 2. METHODOLOGY

### 2.1 STUDY OBJECTIVES

This was a three-year research study (2005–2008) involving five target regions in Canada: Atlantic (Halifax, Fredericton, Moncton), Quebec (Montreal), Ontario (Ottawa), Manitoba (Winnipeg), and Saskatchewan (Prince Albert, Saskatoon, Regina).

The study set out to explore if and how health care providers apply cultural concepts of care in their practice, and the extent to which levels of satisfaction vary with regard to quality of care among Aboriginal people living with HIV/AIDS. It has been our intent to gain an in-depth understanding of the lived experiences and perceptions of APHAs and their service providers in order to identify potential solutions or wise practices that may reduce the negative impacts of culturally incompetent care, treatment and support. The study's three research objectives were to:

- Explore the perceptions of cultural concepts of care among APHAs and HIV/AIDS health care providers;
- Document the lived experiences of APHAs regarding culturally competent or incompetent health care; and
- Design a wise practices guide for HIV/AIDS health care providers who work with APHAs.

Our objectives aimed to develop a set of wise practices from the viewpoint of APHAs by exploring their perceptions of “good care” and how these are associated with relational care by health and support service providers. In turn, our objectives also addressed the issue of wise practices from service providers' perspectives by exploring their perceptions about whether and how relational care improves health outcomes.

### 2.2 STUDY DESIGN

#### 2.2.1 Community-Based Research

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This research study is grounded in a community-based methodology in keeping with the Aboriginal research model of ownership, control, access and possession (OCAP).<sup>30</sup> The OCAP principle is “self-determination applied to research,” as follows:

- An Aboriginal community or group **owns** the information collectively.
- Aboriginal groups or individuals **control** the research process from conception to analysis to dissemination.

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<sup>30</sup> CAAN 2003:23.



- Information and data about Aboriginal people is **accessible** to Aboriginal people.
- Aboriginal groups or individuals have the right to **possess** the data.

At the national level, CAAN represents the community of Aboriginal people living with HIV/AIDS in Canada. The community-based approach is manifested in the research team, whose membership included Aboriginal experts in the field of HIV/AIDS, employees of CAAN, representatives of organizations that are full members of CAAN, and academics with specialties in Aboriginal HIV/AIDS in Canada. The principal investigators and the research team were fully engaged at every stage of the research process, participating regularly in electronic, telephone and face-to-face meetings to ensure continuous interaction and collaborative decision-making. This process created opportunities to learn from each other, refine research questions, discuss and agree upon culturally sensitive methodological approaches, and address ethical considerations on an ongoing basis.

The CAAN National Research Advisory Committee (NRAC) — which includes individual members (APHAs) of the CAAN Network but functions at arm’s-length from the research team — represents the grass roots of the Canadian Aboriginal HIV/AIDS community. NRAC played a significant role in promoting accountability by continually assessing the research study as a reflection of real community needs. “Member checks” were conducted to allow feedback and questions from CAAN members on preliminary findings. In February 2007 and September 2007, public presentations were given at CAAN conferences allowing individual and organizational members of the CAAN Network to comment on the content and direction of this study. For the most part, preliminary interpretations were confirmed by the membership, and useful contributions were made with respect to study protocols.

### **2.2.2 Qualitative Approach**

The research team determined that a qualitative approach was best suited to the objective of understanding the social and cultural context of health care provision. Qualitative methods (semi-structured interviews and focus groups) allowed for interpersonal interaction and provided an avenue from which to gain information on attitudes, beliefs and levels of satisfaction. This approach resulted in detailed descriptions of how APHAs experience their health care world from a social and cultural perspective, and elicited the meanings APHAs assigned to events and practices associated with their care, treatment and support. Similarly, this open-ended qualitative approach allowed for questions to be directed to service providers by the Research Coordinator that were in direct response to what APHAs told us, while also inviting discussion about issues not raised by the APHA participants but of particular concern from a provision perspective.

### **2.2.3 Recruitment**

Community involvement was key to recruitment of APHA participants. Local and regional AIDS Service Organizations (ASOs) and local HIV clinics in each of the five target regions were invited to assist in the recruitment of Aboriginal PHAs. Aboriginal ASOs were particularly instrumental in identifying potential recruitment agencies and, in several cases, undertook to organize recruitment in their region. Ten organizations agreed to place posters advertising the study in waiting rooms, examination rooms and other meeting areas. Each poster had tear-off sheets that could be freely taken by APHAs interested in participating in an interview. Approximately 10 participants contacted the project coordinator directly by calling the confidential toll-free number listed on each tear-off sheet. As well, staff at ASOs and clinics were instructed to make appointments on behalf of APHAs if requested by them. In four of the five study sites, ASO and/or clinic staff organized the interview schedule and provided a quiet and private space where interviews could be conducted. These staff members were essential in brokering the trust relationship between APHAs and the interview facilitator.

Eligibility criteria for participation by APHAs in this study required that participants be an Aboriginal (Inuit, Métis, Innu, First Nations) person living with HIV or AIDS in Canada, that they be 18 years of age or older, and that they had gone to a clinic or community AIDS centre for treatment or care in the past year.

Recruitment of service providers for focus groups and interviews was conducted mainly by direct telephone contact between the project coordinator and personnel at ASOs, HIV clinics and other related organizations known to be accessed by APHAs in the study sample. Local and regional Aboriginal ASOs also provided contact information for service providers known to provide care, treatment and support to APHAs in their areas. Primary (medical) and community-based (support) HIV/AIDS professionals were given the option to participate in a focus group with other service providers in their city or region, or to participate in a one-on-one interview if the focus group schedule was not suitable.

Eligibility criteria for participation by service providers in this study required that participants be currently employed at an HIV/AIDS health care related facility or ASO, that they be 18 years of age or older, and that they had provided services to Aboriginal persons living with HIV/AIDS within the past year.

### **2.2.4 Data Collection**

Two main methods of data collection were used in this study: in-depth, semi-structured interviews and focus groups. Both methods encouraged open and unsolicited responses — explanations beyond mere descriptions — and invited respondents to raise questions of their own. Semi-structured guides (lists of main topics for discussion) were used by the facilitator to steer responses toward relevant study objectives and research questions. This resulted in comparable findings across interview and focus group sessions. Each participant was also asked to complete a background survey form eliciting demographic, cultural, health status and occupational information.

Phase 1 of data collection consisted of interviews with 35 APHAs from five regions of Canada (January to December 2006). In Phase 2 of data collection we returned to each region where APHA participants accessed services, and conducted 11 focus group sessions and 8 interview sessions with primary and community-based HIV/AIDS professionals in those locations (October 2006 to May 2007). In total, 52 service providers participated in the study, representing 25 organizations.

The majority of interviews and focus groups were facilitated by the project coordinator. Several sessions were co-facilitated with research team members in their respective study regions, and one focus group was facilitated solely by a co-principal investigator.

### **2.2.5 Data Analysis**

Each interview and focus group session was transcribed, cleaned of all identifying information, and then coded using ATLAS.ti®, a qualitative analysis program. Data analysis began with “open coding” in which phenomena found in the text of interview and focus group transcripts were identified, categorized and described. Several research team discussions on the integrity and interpretation of code output were facilitated through teleconferences and face-to-face meetings held between April and November 2007. These discussions allowed research team members to agree on coding definitions, present their various perspectives and ideas about interpretations of the data, reach consensus on emerging themes, and prioritize analysis on those themes deemed most relevant to Aboriginal cultural competence as stated in the original research questions.

Information from the background surveys was entered into SPSS® and frequency tables were generated to accurately assess the most salient characteristics of the APHA and service provider samples (see Appendices A and B).

### **2.2.6 Ethics Protocol**

Ethical considerations were guided by the *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans*.<sup>31</sup> This study was originally approved by the Dalhousie University Health Sciences Research Ethics Board in December 2005 and renewed in December 2006 and December 2007.

Participation in this study was voluntary and informed. Each participant kept a copy of the information sheet, which provided a general outline of the nature and purpose of the study and specified the measures taken to protect participant confidentiality and anonymity. Two copies of the consent form required the participant’s signature, one to be kept by the participant and the other to be given to the researcher. The researcher’s copies of all consent forms were secured

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31 CIHR et al. 1998 with 2000, 2002 and 2005 amendments.

in a locked safe in the project coordinator's office. Only the project coordinator had access to the master code lists that match true names to pseudonyms and codes.

Participants were provided assurances that they could withdraw from the study at any point and should they opt to do so, this would not affect APHAs' continued access to services, or service providers' employment, nor would it affect the offer of an honorarium. All participants chose to complete the interview or focus group (no withdrawals), although in the case of several service providers, abbreviated question guides were used to accommodate time constraints.

Each participant was compensated with an honorarium for their involvement in the study. Many service providers initially refused the honoraria, stating that the interview or focus group was held during work hours. In such cases, the facilitator suggested that the honoraria be donated to a "PHA fund" or similar fund managed by the institutions where service providers were employed. Generally, service provider participants were very agreeable to this alternative and accepted the honoraria on behalf of such a fund.

Interview and focus group sessions were recorded (digital and cassette tape) only after consent was given by each participant. Only one participant declined to have their session recorded and in this instance, the facilitator took detailed handwritten notes. All recordings and notes were transcribed by a CAAN research assistant or by a professional transcription service.<sup>32</sup> Transcribers were required to sign a confidentiality agreement. The project coordinator reviewed all verbatim transcripts and removed all identifying information. Each participant was assigned a code number and/or pseudonym, and each location and person named during the session was also assigned a place and name code.

The majority of participants (94% overall) agreed to be contacted again during the course of the study, should follow-up questions or clarification be necessary. Although half of the APHA participants requested to review the transcript of their recorded interview session, only three participants returned the transcripts with minor requests for revision or to indicate their approval of the transcript.

## **2.3 STUDY PARTICIPANTS**

### **2.3.1 Characteristics of APHA Participants<sup>33</sup>**

It is important to emphasize that due to criteria for involvement, the 35 APHAs who participated in this study were accessing medical and/or support services offered in their region.

APHA participants were interviewed in each of the five regions targeted in this study including Saskatchewan (5), Manitoba (12), Ontario (8), Quebec (6), and Atlantic (4). Of the 35 APHA

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<sup>32</sup> Verbatim Ottawa Services.

<sup>33</sup> Appendix A contains tables of all information gathered from the background surveys completed by each APHA at the time of the interviews.

participants, almost all (32) were living in urban centres, including Halifax, Fredericton, Montreal, Ottawa, Winnipeg and Prince Albert. Two APHAs lived in a First Nations reserve community and commuted to the nearest urban centre for treatment. Another APHA lived in a small town and also commuted to a nearby city to attend medical appointments.

Twenty-two of the APHA participants identified as First Nations, with Miqmaq, Maliseet, Innu, Cree, Ojibway and Oji-Cree cultures represented. Most, but not all, of the eight Métis participants lived in western Canada. Five Inuit PHAs participated, all individuals who left Nunavut or Nunavik and had moved to southern urban centres, mainly in central Canada.

Two First Nations PHAs did not have status cards, a limiting factor in terms of accessing non-insured health benefits and other health and support programs aimed at Status First Nations groups. These barriers were also identified by Métis participants who are not eligible for Non-Insured Health Benefits (NIHB), as are First Nations and Inuit individuals.

There was fairly equal representation of male (19) and female (15) participants; one participant identified as transgender. Eight APHAs identified as two-spirit (6 male; 1 female; 1 transgender). In terms of sexual orientation, over half of the APHA participants identified as heterosexual (20), while the remainder identified as homosexual (8) or bisexual (7). Approximately 45% of the APHAs in the study were aged 40–49 years (15), and about one-third (9) were aged 30–39 years. Four participants were under 29 years; five were over 50 years.

By far, the majority (24) of APHAs who agreed to participate in this study were individuals who had been living with HIV or AIDS for longer than six years. At the time of interviewing, two participants had been living with HIV/AIDS for almost 20 years. At the other extreme, five APHAs were recently diagnosed within the past year or two, including one individual who tested HIV-positive just weeks before the interview. It became evident that this APHA participated in the interview in order to learn more about living with HIV and to get information on where and how to access support services.

Age did not directly correlate with years living with HIV/AIDS — that is, older APHAs had not necessarily lived with HIV/AIDS for longer than younger APHAs in the study group. The nine APHAs who had tested positive 10 or more years previously were aged 30–49 years. Those over 50 years old had been living with HIV/AIDS from two to 10 years, indicating they contracted the virus after they were 40 years old. Fourteen APHAs tested positive at ages 20–29 years; 16 tested positive in their 30s and 40s; two tested positive while teenagers, and one tested positive at over 50 years of age.

Five APHAs in the study sample were diagnosed with AIDS. Four of these individuals had been living with HIV/AIDS for six to 20 years, but one had been diagnosed within the past five years. Most (29) were HIV-positive with no symptoms or minor health problems. Of these, six APHAs had been living with HIV for more than 10 years. The most common transmission mode for HIV was sexual contact (21), followed by sharing of needles (e.g., injecting drug use [IDU]) and

other drug works / paraphernalia (8). One APHA contracted the virus through contaminated blood products (transfusion); four were unsure how or when they contracted HIV.

Nine APHAs in the study had attended residential school (of whom three also had a parent and/or grandparent who attended). In total, the parents of 12 APHAs attended residential school; of these, five also had grandparents who attended. Another two APHAs also stated that a grandparent had attended residential school.

### **2.3.2 Characteristics of Service Provider Participants**<sup>34</sup>

A total of 52 HIV/AIDS service providers participated in this study, representing 25 organizations in five regions of Canada. The service provider sample included both primary (medical) and community-based (support) health professionals who work at various types of agencies such as ASOs (both mainstream and Aboriginal-specific), HIV clinics, community health centres, Native Friendship Centres, addiction treatment centres, youth agencies and HIV housing agencies.

Approximately two-thirds (36) of the sample were support professionals composed of social workers, outreach workers, addiction program managers, ASO staff (including seven executive directors), HIV/AIDS educators and Aboriginal wellness coordinators. The remaining third of the sample were medical professionals (16) — including HIV specialists and HIV nurse practitioners — and family physicians who work with APHAs through methadone clinics or other addiction treatment facilities. Regional representation was fairly equal, with the exception of Quebec, where we were able to recruit only three HIV/AIDS professionals.

The service providers who participated are a highly educated group of individuals: 48 held college or university degrees. They brought to the study a range of extensive and prolonged experience in the HIV/AIDS field, including long-term service provision to Aboriginal PHAs. For example, 17 service providers had worked with APHAs for 10–20 years; another 14 had provided services for APHAs for 6–10 years.

Eighteen service providers identified as Aboriginal. Of these, more than half were employed at Aboriginal ASOs (9) or Native Friendship Centres (2). Three Aboriginal professionals worked at mainstream ASOs, two at HIV clinics and two at methadone/addiction treatment centres.

### **2.3.3 Summary**

Taken as a whole, the 87 individuals who participated in this study represented a broad range of individual and organizational experiences in accessing and providing care, treatment and support for HIV/AIDS. Their knowledge of Aboriginal cultural issues and health care systems in various regions across Canada provides a rich source of information and imagination toward building a meaningful and competent approach to care for Aboriginal people living with HIV/AIDS. It is their voices, experiences, stories and opinions that make up our findings presented in the next chapters.

<sup>34</sup> Appendix B contains tables of all information gathered from the background surveys completed by each service provider at the time of the interviews and focus groups.

### 3. THE APHA EXPERIENCE: BEING ABORIGINAL, BEING POSITIVE

Living with HIV/AIDS is often described by APHAs as an emotionally difficult journey that begins immediately after testing positive for HIV. Many of our APHA participants described HIV discovery as a devastating experience, a sudden loss of hope for the future that in other studies has been characterized as “shattered meaning.”<sup>35</sup> For some APHAs, the crisis of HIV has served as a wake-up call to change their lifestyles and to seek what being HIV-positive might mean to their futures. Whatever the initial reaction to discovering their positive HIV status, participants described how pathways to healing can be facilitated by health care and support that nurtures emotional stability, inner strength and, for some, cultural and spiritual renewal.

Service providers generally recognized that APHAs express healing in more holistic terms, where physical, spiritual, emotional and mental wellness intersect. Many medical and support professionals made it clear that living with HIV/AIDS is a lifelong journey, and that many PHAs struggle to deal with a complexity of lifestyle and health issues that led to their HIV infection in the first place. While the journey itself is not Aboriginal-specific, service providers generally agreed that there are cultural components to how APHAs balance positive and negative experiences and how they respond to diagnosis, adhere to treatment, access support, overcome obstacles and learn to live with HIV/AIDS.<sup>36</sup>

#### 3.1 HISTORIC TRAUMA

“Historic trauma” associated with centuries of colonization of Indigenous peoples of the Americas is commonly cited as a main factor in the health disparities experienced by Aboriginal peoples in Canada.<sup>37</sup> Generationally transmitted stress and grief — or “historic trauma transmission” — is the result of repeated relocations from traditional lands and long-term policies of assimilation, including the forced removal of children to residential schools. A “collective contagion” manifests itself in a variety of social and health symptoms in many Aboriginal communities, including learned patterns of dysfunctional family-life and unhealthy sexuality.<sup>38</sup> The intergenerational effect is evidenced by studies showing that young Aboriginal people in Canada are disproportionately affected by poverty, traumatic injury, suicide and other mental and emotional health concerns.<sup>39</sup> For example, researchers commonly consider rapidly increasing rates of HIV and HCV infection among Aboriginal youth as “a reflection of the complex effects of addiction, social dislocation, discrimination, human rights violation and poverty.”<sup>40</sup>

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35 Barroso and Powell-Cope 2000.

36 See also Moskowitz and Wrubel 2005; Smylie 2001.

37 Browne et al. 2005; O’Neil 1986; Spittal et al. 2007; Wesley-Esquimaux and Smolewski 2004.

38 Wesley-Esquimaux and Smolewski 2004:5, 65.

39 Adelson 2005; Waldram et al. 1997.

40 Spittal 2007:236; cf. Barlow 2003; BC Aboriginal AIDS Task Force 2002.

*I find more First Nations families are calling for support. Now we have an individual who has a 15-year-old daughter that tested positive on a Friday and the 20-year old daughter tested positive the Tuesday before. All within one week! And their mom was dealing with all of this but the dad didn't know ... But the dad found out someone has HIV in the community and wants to know. He doesn't realize it's his daughters ... We're finding more family members connected ... You're getting brothers, sisters, mothers, daughters, sons ... being diagnosed. We're having to do more family [counselling] ... and we're finding more and more grandmothers ... are raising their grandchildren and taking care of mom and daughter as well. So doing support with them is very different than in the non-Aboriginal community.*

**Service Provider: HIV educator and consultant, SK**

### **3.1.1 Cultural Disconnection**

Approximately half of the APHAs shared their sense of disconnection from their Aboriginal culture for various reasons. For some, it was because they were fostered or adopted into non-Aboriginal families. Several traced their disconnectedness to attendance at residential schools, or their recent rediscovery of their ancestry, or their regained First Nations status through Bill C-31. For others, traumatic experiences involving HIV stigma, homophobia, ostracism or abusive relationships caused rifts with their families or home communities. Several APHAs left their home communities because of its isolation or lack of services and other opportunities. For these and other reasons, many APHAs concluded that returning home to their communities of origin was no longer an option.

Several non-Aboriginal service providers linked APHAs' struggle for identity with Canada's history of Aboriginal–European relations. One HIV educator claimed that the issue of Aboriginal identity always plays a role in how she provides services, “because I feel that identity was forcibly taken away from the Aboriginal community.” Because certain APHAs struggle with their identity, greater understanding is required by HIV caregivers with regard to APHAs' coping mechanisms, particularly addictions. Several non-Aboriginal service providers acknowledged their patients' resiliency in learning to survive in a discriminatory society, but also observed that Aboriginal identity can be associated with a degree of burden. For some APHAs, being HIV-positive is a sign of failure that brings shame to all Aboriginal people.



*If you're identified as First Nation, or Inuit, and you are drunk on the street, you get the comments that bring shame. It's not just your individual shame. You are held accountable as this emblem of your whole race ... in a way that a white guy on the corner panhandling doesn't have to deal with. He's an obnoxious panhandler, or an aggressive panhandler. But I think that the more you have the strength of pride of who you are — and pride in your history, and pride in the survival of your people — the more painful it is if you feel you're not doing your part, if you're bringing shame on your people. So I think people have extra burdens when they're a member of an identifiable group in a racist society.*

**Service Provider: HIV nurse, ON**

### **3.1.2 Adoption, Foster Care, and Dysfunctional Families**

Seven APHAs in the study were raised in non-Aboriginal adoptive or foster care environments. They told stories about going through an identity crisis as young teenagers, asking questions such as, “Why am I brown? Why are my parents white? What’s going on?” As adults, many of these APHAs do not feel a strong connection to traditional teachings, although exposure to Aboriginal wellness practices, cultural events and APHA peers has for some provided a sense of “coming home.”

*Besides having Aboriginal friends, I don't really follow the sweats or the Native medicine or anything like that. I'm more just, I'm more conventional. And everybody actually, there's a lot of people saying, "Well, because you're adopted into a white family — that's why you do that." I guess, maybe, that does have a role in it. The Aboriginal way — not to sound racist or anything — but I'm just not interested.*

**Wesley<sup>41</sup>, First Nations PHA adopted by non-Aboriginal family**

Wanda was raised in a foster home since infancy and did not know she was Aboriginal until her teenage years. Since testing HIV-positive, she is “on the way of trying to learn things about my past ... my heritage.” Wilma, Oliver and Orville were also raised “in white people’s environment,” but were kept aware of their Aboriginal identities throughout childhood. Wilma was adopted into a non-Aboriginal family in the United States, where her family provided information about her birth parents in Canada. After she tested HIV-positive, Wilma decided to move back to take advantage of Canada’s Medicare plan and to seek out her Aboriginal birth-family. Although Oliver felt removed from his Aboriginal cultural background, his adoptive parents encouraged him in his efforts to learn about his heritage. Throughout foster care, Orville maintained contact with his birth mother who continued to provide support in his journey

<sup>41</sup> Pseudonyms are used for all APHAs quoted and referred to in this report.

with HIV/AIDS. Sam and Sally were both fostered as children, but maintained contact with their respective parents. At the time of interviews, they were living on Sam's reserve but were having difficulty "fitting in because everybody speaks Cree over there." Sally added that she "grew up in jail" and spent at least half of her life living in the city where both she and Sam "felt more comfortable."

Several APHAs withdrew from their Aboriginal cultures and communities because of a dysfunctional family life. Oscar "isolated" himself from his family when he came out of the closet and because of alcohol abuse within his family. Molly also spoke about her "family problem back home" and explained, "I left my community because of the bad memory I had at a young age." Odell described how he "lost his identity" as a result of being [sexually] abused by family members.

*I lost my identity when they did that to me. I couldn't practice it anymore. So now I lost that identity ... As a child and when I grew up, I was into that. But as an adult I'm not, because the two men who [abused me] — I'm really sorry they did — but I lost that part of my life. I really would like to get back into it, but I can't because I've lost so many years of contact with my community. I don't feel that ... I'm sorry to say.*

**Odell, First Nations PHA**

Service providers observed that their Aboriginal clients tended to possess a strong sense of family but that perceptions of family were either very positive or very negative. An Aboriginal addictions counsellor suggested there is "a huge family dichotomy problem with our population ... You either have a really strong family support or you have absolutely none ... A lot of our population is separated from their family." Two physicians interviewed emphasized "strength of family" in the Aboriginal community, adding, however, that this can be "both a blessing and a curse" depending upon how "functional" the family is. They indicated, too, that their Aboriginal patients seem to "suffer a great deal of sorrow" related to premature deaths in their families ("My sister died;" "My brother committed suicide"). HIV/AIDS adds to the sorrow for families who have several members diagnosed HIV-positive.

### **3.1.3 Residential School Legacy**

Four APHA participants stated that their health was negatively compromised by generational effects of residential schools. These individuals spoke about family breakdown that included sexual abuse; lack of parenting skills; addictions; and loss of culture, language and identity. In the view of these APHAs, their parents' experiences led to unhealthy sexuality and high-risk behaviours in their children's lives, resulting in vulnerability to HIV transmission. The nine APHAs who themselves attended residential school declined to comment directly on how this may have affected their health status, or believed there were no effects at all. Nevertheless, in the course of interviews it became evident that attendance at residential school was a factor

in the cultural disconnection described by APHAs. Previous studies by CAAN support these findings. In a national survey of 195 APHAs conducted in 2004, 16% indicated they attended a residential school, and almost half (48%) reported that a parent, guardian or grandparent attended residential school. Health effects included poor mental health (including low self-esteem) as a result of psychological and physical abuse, and tendencies toward high-risk behaviour (addictions, unhealthy sexuality). Comments regarding poor parenting and family breakdown suggested that APHAs lacked family support in their struggle to live with HIV/AIDS.<sup>42</sup>

Before Orville was placed in a foster home, he spent several years in a residential school, an experience that continued to cause stress in his life: “The more I think about it, the more it gets me upset.” Murray said the residential school he attended was not itself a negative environment, but the result was loss of Inuktitut language skills and distanced family relationships. Winston’s first language was “Métis French” but he “had to learn English” when he began attending school in “an English town with English kids.” Owen lived on his reserve until grade 9, when he had to leave to attend high school in the city; since that time he seldom returns to his home community. Stella refused to stop speaking Cree at boarding school “no matter how many lickings I got” and has maintained a strong connection with traditional activities such as trapping. However, being HIV-positive and on anti-retroviral (ARV) treatment, her activities on the land are now restricted. Susan also said that after residential school she was disconnected from her language, her home reserve and her culture.

*I'm originally from [First Nation] but I've never really lived on my reserve. I moved out when I was six years old ... When I went to boarding school all I knew was Cree. But by the time I got out, all I knew was English. So I completely forgot my Cree. I was more or less brainwashed when I was going to boarding school. Right now Cree is not important to me because I don't understand it. I'm not really involved with my culture.*

**Susan, First Nations PHA**

A few service providers suggested that APHAs’ choices to pursue traditional wellness practices depended on whether they were residential school survivors. An Aboriginal treatment counsellor who was involved in “healing around the residential component with a group” in her city reported that some individuals had “a lot of struggle around spirituality after that, and it’s generational.” In her experience, Aboriginal clients of ages 30 and under are more likely to be open to traditional practices, but for older individuals, “there is still a bit of something going on there.” The executive director of an Aboriginal ASO agreed that “for the most part, there’s a split between traditional Native people and non-traditional Native people.” An HIV physician who works part-time with an urban Aboriginal community health centre stated that the residential school legacy is one reason why “finding the path to a healthy Elder is not necessarily a straightforward one.”

<sup>42</sup> Jackson and Reimer 2008:13.

*There's that conflict. "You shouldn't be beating that drum, you shouldn't be taking those medicines. That's a whole bunch of hocus-pocus." And then you've got the other traditional people saying, "No, I'm reclaiming my tradition and I want to do this." So you've got that conflict there.*

**Service Provider: Aboriginal ASO staff, Atlantic**

*It's not only the understanding [about HIV/AIDS], but sometimes ... there might be attitudinal problems there in terms of injection drug use, in terms of homosexuality, and some of the Elders struggle with it very much. And they'll bring what I see as a somewhat Christian interpretation of traditional spirituality into it, which is an interesting mix. But that's not helpful and in fact can make people feel even more alienated from their spirituality ... Sometimes there is confusion around traditional spirituality versus Christianity and I think some of that has certainly been the experience from residential schools and the generational impact. Some of it, too, has to do with [APHAs'] experience of traditional ceremonies: not only being able to access an Elder or ceremonies, on one hand — particularly if they're in the cities — but on the other hand, if they do have access, what was that experience like? Was it a healthy Elder?*

**Service Provider: HIV physician, ON**

### **3.1.4 Mobility, Migration and Transience**

Traditionally, many Aboriginal groups moved in semi-nomadic patterns based on regular seasonal cycles of resource harvesting. While the reserve system for First Nations people, and centralized settlements for Inuit and Métis people, introduced more sedentary lifestyles, it also resulted in mobility patterns from rural and isolated communities to larger urban centres. These movements were for a variety of social and economic reasons including employment, accessing medical facilities, or seeking alternatives to isolated or rural community environments. A recent study of Aboriginal youth in British Columbia reported increased HIV vulnerabilities due to mobility and migration between reserve communities in northern B.C. and Vancouver's downtown eastside.<sup>43</sup> CAAN's national care, treatment and support survey found that almost 40% of the APHAs in that study had already moved, or stated they would need to move, to be nearer HIV/AIDS services.<sup>44</sup>

Service providers in this study also viewed Aboriginal populations as more transient with high rates of mobility between home communities and urban areas, sometimes involving short-term residence in multiple locations, often interspersed with time on the streets. Transience,

<sup>43</sup> Spittal et al. 2007:228.

<sup>44</sup> Jackson and Reimer 2008:10–11.

homelessness and unstable housing present serious challenges to HIV drug adherence among the APHA patient population, and service providers observed that APHAs tend to vacillate from times of chaos to times of stability. For example, three HIV nurses from different regions described how their Aboriginal patients' treatment adherence and health outcomes were compromised by "chaotic" lifestyles.

*One of the issues of adherence is to develop a regular pattern in your life ... taking your meds at the same time. So, if your life is a little more chaotic, if you have difficulty with housing, if your life is not quite stable, then it does become more difficult. Certainly difficulties with adherence a lot of times is identified with addictions. And then [there are] a fair number — at least the numbers that we see ... [with] very high addiction rates within the Aboriginal population.*

**Service Provider: HIV nurse, QC**

### **3.2 SHATTERED MEANING: HIV/AIDS DISCOVERY EXPERIENCES**

For many APHA participants, an HIV diagnosis can shatter the meaning they hold about life and their place in the world.<sup>45</sup> Often respondents described how testing positive for HIV resulted in overwhelming fear that illness would quickly lead to crippling illness and/or sudden death. For some, coping meant withdrawing from social and family supports. For others, HIV was viewed as a punishment for past high-risk behaviours, including sexual practices or substance abuse. Frequently, APHAs' lives entered a period of intensified negative coping based on past street involvement and substance abuse, often reflecting the same high-risk behaviours that led to the diagnosis in the first place.

*I still don't accept this disease I am carrying ... So for me, I had my suicidal thoughts way at the beginning when I was diagnosed ... When I was diagnosed, when I went into emergency, when they told me I was HIV-positive, then the next day I felt like, no tomorrow. I felt like my life was so low that I didn't know how to put it back up, like where I'm at now. Before, I was down, depressed, lonely, lost, confused, didn't know who to go to. I didn't know how to share my story with my family saying that I was diagnosed with HIV. I didn't want to scare them. I didn't want them to get stressed out. So I kept a lot of things to myself.*

**Molly, Inuit PHA**

<sup>45</sup> Barroso and Powell-Cope 2000.

### 3.2.1 Am I Going to Die?

APHAs often spoke of their diagnosis with HIV/AIDS as followed by a period of devastation and hopelessness. Mary, for example, became very emotional when speaking about her diagnosis experience that for her followed the birth of a child. She worried that HIV meant that she might soon die, and she believed that this worry and emotional distress caused her immune system to “go down very fast.” Several other participants feared that their diagnosis would imminently lead to illness or death — a situation they perceived as the result of being HIV-positive and worsened by the emotional stress of the diagnosis.

*I was at the woman's shelter with my newborn baby and the doctor called me so I went to see him. He told me, “I'm not trying to scare you but I have to tell you the truth.” And I asked him, “What?” “You're positive.” “What do you mean I'm positive?” “You're HIV.” That was scary in the beginning when you hear it and start to think, “Am I going to die first, before anybody dies?” You know? (softly crying)*

**Mary, Inuit PHA**

A consequence of shattered meaning is a loss of a future-oriented perspective. Several APHAs in this study revealed that they had suicidal thoughts when first diagnosed. This was followed by the reality of living with HIV, which offered little in the way of reprieve from physical and emotional reminders of being positive. Primary health care providers who either must report the diagnosis, or are present when the diagnosis is revealed, have learned that for many individuals, the “automatic” reaction is that “it's a death sentence.” An Aboriginal HIV nurse said her strategy is to help individuals understand the “grieving process” associated with the diagnosis, and in this way find common ground on which she and the APHA patient can connect.

*I was pretty devastated. I feel like committing suicide because I know it's ... I still don't feel good but I feel a little bit better now that I'm starting to cope with it. Like deal with it in my head. But I thought it was the end of the world when I found out.*

**Otto, Inuit PHA**

For others, at least initially, a diagnosis of HIV was something to be ignored. Walter shared that he “didn't care if (he) lived or died.” This period of resignation lasted several years, and it was only recently that Walter made a conscious decision to deal with HIV by seeking medical care. Among APHAs whose health had remained fairly stable the period of resignation continued, and they had, up to the time of the interviews, refused treatment altogether.

*There was no peace, there was no happiness, there was no joy in my life. There was just, I was just going through the motions ... I'm not living my life, I'm just existing. And then one day, "I've got to do something. I can't go on like this!" And I made the decision I wanted to live. So I stopped doing drugs, stopped drinking, started taking multi-vitamins, started eating properly, started exercising, trying to reduce the stress in my life, and see my doctor regularly.*

**Walter, First Nations PHA**

### **3.2.2 Intensified Negative Coping Experiences**

According to service providers, any person living with HIV/AIDS demonstrates both positive and negative ways of coping. The most common observation — particularly concerning PHAs infected with HIV through injecting drug use — is a return to and intensity of coping through substance abuse. Several APHAs spoke about periods of intensified addictive behaviour as an initial coping strategy. Sam and Sally shared how they kept busy “on the street” and “shooting up.” Olivia said that for six years after her diagnosis, “booze was my medication.” Walter rationalized that, “I have five years left, and I’m going to make it one big party.” For Stella, a woman infected with HIV as a result of a criminal assault, an HIV diagnosis represented the trigger to first-time injecting drug use. Service providers observed that some PHAs’ lives revolve around on-again/off-again, using/clean cycles of addictive behaviour as they deal not only with their illness, but with a variety of deeper emotional and psychological issues as well.

Service providers recognized intensified negative coping as a stage toward acceptance of being HIV-positive. An addiction treatment professional described the cycle as a series of stages in which all APHAs initially experience anger and resistance to their diagnosis. For some, acceptance is illusive and self-destructiveness is often the result. As one service provider shared: “A lot of them ... will hit the street twice as hard as what they’ve already been doing.”

### **3.3 OBSTACLES ALONG THE PATH: RACISM, STIGMA AND HOMOPHOBIA**

For most people diagnosed with HIV/AIDS, the shame and failure associated with experiences of stigma and homophobia further complicate HIV discovery. For some, they represent already well-recognized barriers to disclosure and to accessing treatment and support services.<sup>46</sup> At times, individual participants’ perceptions of stigma also further complicate the already tenuous dynamic between patient and caregiver.<sup>47</sup>

<sup>46</sup> Herek 2002; Vance and Denham 2008.

<sup>47</sup> Wight et al. 2006.

Service providers say that HIV stigma and racial prejudice tend to limit APHAs' access to medical and support services, both inside and outside Aboriginal communities. Inside home communities, access to services is limited by APHAs who are concerned about privacy and confidentiality. Outside Aboriginal communities, attitudinal obstacles in the paths of APHAs' healing journeys include APHAs' perceptions of discriminatory practices by social assistance agencies, pharmacists, clinicians and other mainstream service agencies. For APHAs, racist attitudes toward Aboriginal peoples within health care and support environments add another layer of stress to an already difficult situation. APHAs' perceptions of prejudice were often woven into and associated with stories of racism, HIV stigma and/or homophobia. It is these issues that continue to pose obstacles to healing for Aboriginal PHAs.

### 3.3.1 Racism: “Another Indian Junkie”

Participants who related experiences of perceived racism did so almost exclusively within the context of primary medical services. In particular, there was a perception that health care professionals associated Aboriginal identity with addictive behaviour. Walter described a particularly bad experience when he had a high fever and went to the hospital emergency ward where, although he disclosed that he was both Hepatitis C and HIV-positive, he waited for “about six hours” until he eventually fainted. When the nurse later noticed fresh tracks on his arm, she said, “ ‘Tsk!’ and shook her head,” actions which Walter interpreted as “here’s another Indian junkie.” Wanda told how a locum doctor discontinued her pain medication “because he didn’t want to contribute to addictions.”

*I’ve been to clinics when I’ve had an injury — whether it was due to drinking or not even drinking — that I think I felt a prejudice where they just kind of came in and took a glance and [said], “Oh, yeah, you did something stupid when you were drunk. And it doesn’t really matter because you’re just an Indian, and you’re probably going to just go get drunk and do it again.”*

**Oliver, First Nations PHA**

City hospital emergency wards were repeatedly identified by APHAs as places of perceived racism, particularly with regard to their triage practices. APHAs in every study region spoke with disdain about the long wait times at emergency wards, and many shared stories about non-Aboriginal patients seemingly favoured over Aboriginal patients. For example, Wanda, Arlene, Sara, Sally and Sam each believed that their long waits at emergency wards were because they are Aboriginal. Sara said she waited four hours and was uncomfortable with the way they looked at her and talked to her. Sally said “they take white people right away” and Sam agreed that it seems, “they’re prioritized over us.” At a hospital further north, where service providers might at least potentially be more familiar with Aboriginal patients, Sam and Sally said “they don’t treat you like a person over there.” When asked about her experiences with medical professionals, Opal replied that the nurses at the hospital “treat you really rough, and they show that they don’t like you.”



*When I went to the [hospital] it was ... you're waiting, and waiting, and waiting. It just seemed like it's for the white people ... It just seemed racist and it seemed like they thought I was out for drugs, just because they knew that I was on methadone.*

**Wanda, Métis PHA**

Racist attitudes were also perceived in terms of dominance of the western biomedical model of health care over alternative, complementary or traditional wellness practices. Allen said he “got attitude” from a nurse in the HIV clinic when he tried to explain his traditional healing practices. In his opinion, she conveyed that “the white way is the right way, is the only way.” Allen also felt that the local mainstream ASO was biased toward “white ways.”

*There's a significant level of prejudice ... a significant level of ignorance, and significant barriers to care. People being judgmental, often without thinking that they are. I think it's just become a dismissive way of dealing with people. This is as much with regards to addictions as anything racial, I think.*

**Service Provider: Physician, methadone clinic, SK**

Physicians who have spent considerable time in their careers treating Aboriginal patients for addictions and/or HIV/AIDS note with dismay the high level of prejudice that remains within their profession. The executive director of an HIV/AIDS support agency observed that many PHAs, especially those who belong to “marginalised” groups, do not trust medical professionals. Discrimination experienced by Aboriginal clients at clinics includes being “asked more personal questions by doctors.” This seems to be particularly true for injecting drug users of whom “doctors seem to think it is their role to ask questions.” In particular, Aboriginal-looking women seem to be asked many more personal questions than are non-Aboriginal women about their sexual activity, number of children or state of housing. Prejudicial attitudes have also been observed at pharmacies where APHAs requesting pain or other medications have been asked questions about drug abuse and were assumed to be addicts. A traditional Aboriginal healer suggested that the coping skills used by APHAs have developed out of adversity and within a health environment where they perceive they will be stereotyped.

*In regards to the coping skills, I find that there seems to be a stereotypical image being placed onto [APHAs]. If they've gone through adoption and fostering or an unhealthy upbringing, or whatever ... they develop those coping skills. And I find that if they have come from a rural place, say a reserve, and have gone through an adoption, that is something they have a difficult time expressing and opening up to, let alone some of the other abuses that they have come upon ... And my question is: How many have disclosed the fact that they come from a reserve, or are Métis, or Inuit? Because there's a stereotypical image, I believe they develop a coping skill to not mention that.*

**Service Provider: Aboriginal healing and wellness coordinator, ON**

Discriminatory and prejudicial attitudes at social assistance agencies were singled out by several service providers interviewed. Staff at a community HIV health centre encountered such attitudes on numerous occasions, especially in connection with disability income assistance for PHAs: “It’s very subtle, but they stereotype people.” For non-Aboriginal clients, support staff prefer to encourage them to speak up for themselves. However, for Aboriginal PHAs, support staff are more inclined to intervene because in their experience, “racism plays a big role in some government agencies . . . It’s not a thing we can prove, otherwise we’d go to the Human Rights Commission.”

*If someone comes to see me and they’re talking about how their welfare worker or [Social Services] is giving them a hard time, I start to reflect on whether that may be because of racism, oppression, colonization ... that they may be experiencing difficulty because of those issues. And so I think it’s important when I work with people who are of Aboriginal descent about giving time, being respectful and talking to them about their experiences ... Because I sense it’s extremely hard for them ... My experience with a couple of clients is that they’ve had a lot of difficult times with [Social Services].*

**Service Provider: HIV health centre support worker, MB**

### 3.3.2 HIV Stigma: “We’re Only Human, It’s Just a Disease”

Virtually all APHA participants spoke about confronting HIV stigma. Participants described stigmatizing reactions of friends and family or when accessing community health services. These reactions reinforced their internalized images of what it means to be living with HIV, and participants often described a fear of rejection as their reason for not disclosing HIV status to family or friends.

From a medical services point of view, HIV stigma in Aboriginal communities discourages HIV testing and threatens to isolate APHAs from important family support networks. An HIV nurse specialist described the climate in some communities as “extremely toxic,” leaving APHAs in a very vulnerable situation. Several of her patients said they “would fear for their life” if their HIV status was disclosed. The threat of being ostracized by their own communities deters APHAs from disclosing their HIV status and consequently from seeking either medical care at local health centres or traditional wellness care from their Elders.

*There is some resistance to being tested ... There is still a lot of stigma and I think more so in the Aboriginal population ... I’ve had [First Nations] reserve authorities phone me and say, “Can you talk to our nurse? She refuses to tell us who in the reserve is HIV-positive. And we need to know that so we can protect ourselves.” So I say, “Well ... no. Your nurse is absolutely right. You have no right to know that and you don’t need to know that to protect yourself.” But there is that view.*

**Service Provider: HIV physician, SK**

Molly said visits to her home community in the north have been difficult because the nurse's station is afraid to treat her. Their attitude seems to be: "Take her, I don't want her." Wesley had a similar experience in the hospital on his reserve where he felt "kind of — what's the word? 'prejudice' — like they didn't want to be near me." Aboriginal service providers also described how HIV stigma in home communities either creates or reinforces cultural disconnection: APHAs may want to access traditional ceremonies and wellness practices within their own community, but cannot because others are fearful about being infected. An Aboriginal support worker was once told by a community leader, "We don't want anybody sweating with us who has HIV, because we don't want to catch HIV if we're in a sweat." In the view of this Aboriginal ASO staff member, such an attitude demonstrates "cultural incompetence in our own community."

APHAs also experienced HIV/AIDS-related stigma in hospitals, community clinics and dentist offices. Wilma had a particularly stressful experience when she was refused treatment for an ear infection by a specialist, and she was pursuing legal action on the grounds of HIV discrimination. At one point, Allen was afraid that attitudes associated with "AIDS phobia" among paramedics and emergency staff put his life at risk because the triage team "didn't want to deal with a faggot with AIDS." Arlene and Annette live in the same region as Allen and have also had problems related to HIV/AIDS stigma in area hospitals. When Arlene was convinced she had pneumonia, she disclosed her HIV status to emergency ward staff and "felt discriminated against" as numerous other patients were prioritized over her. After "nine hours" Arlene finally "gave up" and went home.

When asked why she thought this happened, Arlene replied, "I assumed because I was an Aboriginal with AIDS." Annette has written "many letters over the years" about the local hospital's treatment of HIV patients, particularly about the lack of confidential communication between staff. Loud verbal exchanges between nurses and technicians have left Annette feeling hurt and angry, "like you were having a big light shining on you, and you're different, and you're going to be contagious." Annette had a fairly low opinion of dentistry as well: "I disclosed to my dentist, and his first question was, 'How did you get it?'" Stella had a similarly low opinion of social services agency attitudes toward PHAs, and said she has learned to fight the system to get what she needs.

*Social services ... nobody wants to deal with me. I just get shifted from one person [to another]. For awhile, here, they had this one good worker, but she got married and her husband took her away. But she was a real good worker. She dealt with people with HIV and like she wasn't scared to touch people and stuff. She knew about it, she was educated. I'd like for somebody to go talk to those people ... I've tried and they won't let me. We're only human. It's just a disease. It's not as contagious as the bird flu or, you know, stuff like that. But they seem to think it is. [Q: Are you still able to get what you need?] If I bitch long enough I'll get it.*

**Stella, First Nations PHA**

### 3.3.3 Homophobia: “I’m Labelled as Gay”

Service providers frequently commented on the burden being placed on APHAs’ sense of Aboriginal identity due to homophobic attitudes and associated fears about HIV/AIDS. This is a serious concern for APHAs who have been judged by and are now unwelcome in their home communities. Oscar believes that the reason “Elders don’t want to discuss [HIV/AIDS]” is rooted mainly in homophobic attitudes.

*I find that the harshest way that people are hurt is through this voice ... when [APHAs] say, “I’m not going back there because I’m labelled as gay.” And [the community says], “Well ... no, Aboriginal people are not gay.” Well I’m sorry to say, we are human beings, and whatever your sexual preference is, that is going happen as you mature in life. But there’s that thing, that stigma that comes out: “No we will not put up with your [sexuality]. No, this is not the way ... There’s no homosexuality here, or no lesbianism, or whatever.” So it’s like it’s behind closed doors ... So if you become infected [with] HIV/AIDS, it’s like, “Oh God, I can’t go back there. Because I know what that community is going to be like. I’m criticized. I’m known for a wrong choice that I made in my sexuality preference and whatnot.” So that is my personal feeling: a lack of those types of awareness and services that are available. But I find that one of the harshest [things] when people talk about homosexuality or lesbianism is [when they say], “You can’t talk about that!” or you get slapped on the wrist. So [for APHAs] it’s like, “Why should I go back to that environment?”*

**Service Provider: Aboriginal healing and wellness coordinator, ON**

Homophobia was also frequently identified by APHAs as factors in their cultural disconnection. In his youth, Oscar pulled away from his family and community when he came out of the closet and chose to identify with the “gay community.” William, who divulged that he had been sexually abused by a family member, believed that as a gay man he was not accepted by his community “for who he really was.”

*I was never really allowed to be myself. Like, from an early age, you’re not allowed to be who you are. I mean by that, I’m saying, I knew I was a gay man, but based on that whole church upbringing and societal and familial [atmosphere] ... and then being assaulted by someone within the family, a brother ... so you think, “Okay, who then can I trust?”*

**William, Métis PHA**

*I left home young. I came out of the closet and got all that negativity and that shit, and left home and never turned back ... I wasn't being accepted. There [was] a lot of verbal abuse and a lot of emotional abuse. It wasn't so much physical, there was no physical abuse. It was all mental, and emotional, spiritual ... But like I said, going through those years, I had the contact of my Aboriginal family but when I left home, and I came out of the closet, I found another family that accepted me for who I was and that was the gay community. They gave me more love and support and understanding than my own family.*

Oscar, First Nations PHA

### 3.3.4 Pushed and Pulling Away from Family, Community and Treatment

APHAs with overlapping identities — Aboriginal, HIV-positive, gay, an addict and a sex worker — described pulling away from familial and medical relationships in an effort to protect against painful experiences of stigma, racism or homophobia. Several APHAs said they coped with these emotions by keeping things to themselves rather than seeking counsel or support from family, friends or professionals. Wilma and William, for example, each went through a period of denial and did not seek medical care or support for the first few years after testing HIV-positive. Both Murray and Marc said they did not get involved in talking circles<sup>48</sup> because they each preferred to “deal with this myself and on my own.” Arlene wished there was “a way to forget” that she has HIV.

*I think the first time I took sick, which was back in June, July ... August, when I took really sick, very sick. Before then, I was telling the doctors that I don't feel right, I feel like I'm dying. I feel like I'm stuck in this hole and I can't get out of it. I was really very depressed, you know? And they asked me if I was suicidal. I said, “I might have thought about it a couple of times, but it just went away again.” But I was thinking about my grandchildren, about dying, about ... Every time I'd get sick, I'd be laying there, “Oh I'm going to die tomorrow,” and ... I think I could have used somebody to talk to, maybe once a week or so, but my family doesn't understand what's going on ... And other days, I just wish there was a hospice somewhere I could go stay, instead of being with my family making me have so much stress, you know?*

Arlene, First Nations PHA

<sup>48</sup> Talking circles or healing circles are an Aboriginal method of deeper communication within a group based on sharing, cooperation and respect. A sacred object such as a carved stick, feather or stone is passed around the circle of individuals in a clockwise direction. An individual in the circle cannot speak until they hold the object, nurturing careful listening and learning to craft their words when their turn to speak arrives.

APHAs and their service providers spoke about fear factors that affect decisions to return to home communities, or that explain their disassociation from Aboriginal events in their current urban homes. Marc's relationship with his family and home community is difficult partly because he was raised in "white country," but mainly because they neither understand nor accept his HIV status. Several health professionals related stories about Aboriginal PHAs who felt they could not return to their family or their reserve because they were HIV-positive. An Aboriginal HIV nurse shared a story about an APHA's family who vigorously resisted counselling "because if I talked about it, I brought it into their home."

*My village is very hard for a guy like me with HIV. It is very hard to make a life there ... people are afraid.*

**Marc, First Nations PHA**

The executive director of an Aboriginal ASO emphasized the importance of family, stating that Aboriginal people "have different value sets" when it comes to living with HIV/AIDS: if access to treatment means moving away from home, "most people would suffer through the disease that they're living with, just to be with their family." This "value set" makes it all the more difficult when prejudicial attitudes separate APHAs from their families.

*There are families that know that they have a family member who's HIV-positive, and support them and help them. And that's awesome. But it's not the common theme throughout. They have to hide their status ... and sadly, some of them die alone. And when I do my workshops, I stress that some of the people who have HIV, they just want to come home to their home communities, to die with dignity. And they can't do that.*

**Service Provider: Aboriginal HIV educator, Atlantic**

*One individual was told to leave the community because they were positive. And the family were made to feel like they've done something wrong because the person wanted to come home and be with their family. It's so sad to think that people today are still being discriminated against even when they're just trying to survive, even when they're just trying to look for support and cope with their diagnosis. They go home thinking, "I'm part of an Aboriginal community, I have been taught this sense of family and well-being, but then when I come home with HIV it's, "You can't come here."*

**Service Provider: Aboriginal ASO staff, Atlantic**

A lack of community support is difficult — not only for APHAs, but also for their families who continue to live on First Nations reserves, Métis settlements or Inuit hamlets. For this reason, medical service providers have been compelled to devise creative solutions to maintain confidentiality, particularly when pressured by a Band Council or local health centre for

more information regarding reasons for medical transport, or when the Council believes this information is necessary to protect the community. The fact that many APHAs come from small communities where local health centre staff will almost certainly know individuals' families creates a need for outside HIV clinics to tighten privacy and confidentiality protocols.

In larger urban areas, some Aboriginal clients prefer to attend a clinical environment where there are no Aboriginal staff because this lessens the risk that staff will know friends or relatives from their home community: "They feel a little safer ... it's not only confidentiality ... it's more about being anonymous." Paradoxically, fears about compromised anonymity limit the reach of Aboriginal ASOs who report that some APHAs are afraid to access these services because "everyone knows everyone." In cases where APHAs forfeit monthly financial support from an Aboriginal ASO, this is a high price to pay for anonymity.

*Definitely, there's a different culture, or support system, from First Nations people compared to [other] people we've dealt with. Everybody's related, and so sometimes it's a barrier. I know we've had many people who don't want anything, any piece of [paper], any lab test ... they're very, very nervous that anything will go to their reserve because they're such a small close-knit community. Everybody knows everything. And so, for confidentiality, they're very ... very concerned about that ... Sometimes we're not allowed to phone them on the reserve. They'll call us. We can't send letters in some cases, because everybody looks at everybody's mail that comes in. So we try very hard to be non-identifying with anybody with HIV/AIDS, but I believe it's more of a concern in First Nations communities, in our area.*

**Service Provider: HIV nurse, SK**

### **3.4 MOVING FORWARD ALONG A "BETTER PATH"**

For some of the APHAs in our study, being positive has been a turning point in their lives, leading to a "good journey" or "better path." More than one-third of the APHAs interviewed talked about reconnecting with their Aboriginal heritage since testing HIV-positive. Reconnecting with their culture is a means of seeking new meaning in life, learning to take pride in being Aboriginal and generally improving self-esteem. Aboriginal cultural activities (ceremonies, powwows, feasts, arts and crafts) help APHAs to stay away from street culture and provide a place to meet with Aboriginal peers. Other APHAs did not seek cultural or traditional avenues to find meaning in living with HIV/AIDS, but nevertheless viewed HIV as an opportunity to grow. Other studies have also documented how, for some, HIV is seen as a "gift" that triggered reflection, introspection and "re-evaluating life priorities."<sup>49</sup>

<sup>49</sup> Barroso and Powell-Cope 2000: 341.

### 3.4.1 Catalyst for Change: Finding Meaning

An HIV physician and an HIV nurse specialist who provide services at an inner-city drop-in clinic interpreted APHAs' experiences as a "cycle" in which the experience of trauma leads to high-risk behaviour, resulting in HIV infection — a diagnosis that acts as a "wake-up-call" to deal with the trauma and to seek healing and wellness. They lamented the frequency of HIV infection as the catalyst for change in the lives of many APHAs.

*Is there something out there that can be the wake up call, or the alarm clock before the HIV? ... Please, is there something that we can do, before they have to get that wake-up call?*

**Service Provider: HIV physician, ON**

*Can we find better ways? That's how I feel with clients that explain to you ... that if they hadn't found drugs in their teenage years, they're convinced they would have been dead because they were dealing with trauma ... Obviously this is not just Aboriginal [PHAs], by any means ... But they were in this terrible, terrible pain and the only way out of it that they knew was suicide, but they found drugs. So they feel drugs helped them survive. Now drugs helped them survive at that point, but then created other issues for them, created health problems, and on and on. So that then they're left with the rest of their lives, trying to sort it out ... And it's a comment on our society's failings that we are leaving the kids with drugs and alcohol as the saviour they find at that point.*

**Service Provider: HIV nurse, ON**

A few APHAs specifically pointed to being HIV-positive as the trigger to reconnect with their Aboriginal culture. When Wesley tested positive, his Aboriginal friends suggested that he go to the community HIV health centre where the Aboriginal programs peaked an interest in learning about his cultural heritage. Allen was also encouraged to pursue Aboriginal teachings and traditions when his aunt found out he was HIV-positive. She counselled him that through the "eagle feather and the sweet grass, he'll find the strength to live with this HIV and AIDS."

From service providers' perspectives, APHAs who reach a stage of acceptance have the unique opportunity of returning to their cultural roots and to turn things around by seeking healing and wellness through traditional Aboriginal paths. A Métis addictions counsellor has worked with many APHAs who have begun to "explore who they are, their identity, their culture" as a pathway "to heal ... to better themselves." Compared with non-Aboriginal PHAs, service providers said that it is their Aboriginal clients who are most likely to hold the view that HIV/AIDS is a teacher and guide in their healing journey. The executive director of a mainstream ASO made the same observation, stating that APHAs' view of HIV as "a lesson" or "a gift" is



“diametrically opposed to how our other members might see it” and is important to recognize in terms of “how they understand their own bodies and themselves.” It is this view of HIV/AIDS that marks the turning point in APHAs’ healing journeys.

*One of the things that I’ve heard from Aboriginal PHAs that I don’t think I’ve ever heard from non-Aboriginal PHAs is this idea that HIV, their diagnosis, in some ways made their life better. Because HIV is like a teacher. HIV is put on this earth for a reason, and it’s not to punish you for your sins! ... It comes across from a lot of Aboriginal PHAs who said, “I’d probably be dead right now if I hadn’t been diagnosed. I was on a crash course to destruction and I got my shit together after I got diagnosed.” So that is one thing that I can think of that ... their diagnosis is in some way a positive influence on their lives.*

**Service Provider: Métis HIV support worker, MB**

*Initially, the coping skills were very negative. Alcohol and drugs as a way to cope; eating, gambling ... After the initial coping skills, some of the APHAs have turned it around and have come back, and have gone to the Elders and finally accepted their diagnosis and decided to either go the route of traditional healing practices, or contemporary medicine, or both ... I think the thing that is unique to Aboriginal PHAs is the choice that they have of either going the traditional route, the contemporary medicine, or a combination of both. I think that would be unique among APHAs.*

**Service Provider: Aboriginal ASO staff, Atlantic**

### 3.4.2 Caring about “The Real Me”

*At the beginning I didn’t know how to stand on my two feet and be strong, but now I’m on my two feet ... this is why I like me, the real me. Not the drunken Molly, the real me.*

**Molly, Inuit PHA]**

The concept of “health-within-illness” illustrates how individuals who experience illness emerge feeling healthier than before they were diagnosed.<sup>50</sup> Ironically, the traumatic experience of testing positive for HIV can be a valuable resource of personal growth in the form of learning health-promoting behaviour.<sup>51</sup> Similar to other studies on HIV individuals, APHAs in our study shared how focussing on the self provided a sense of control over HIV — and these actions

<sup>50</sup> Taylor 2001.

<sup>51</sup> Boerum 1998.

helped to reduce uncertainty about health matters. Many APHAs we spoke with were in recovery and had stopped high-risk behaviours associated with addictions. Similar to the study by Barroso and Powell-Cope, several of our study participants engaged in “the everyday work of living with HIV,” including volunteer activities to keep busy and off the streets, and taking active steps to reduce stress and maintain a positive attitude. During interviews, a few participants asked for advice and information on how to become engaged in HIV-related activities in their local area as a means of connecting with peers and perhaps finding new purpose in life. Several APHAs demonstrated a palpable sense of “positive affirmation of life and self” and explicitly acknowledged the “critical link between the mind and body, and that changes in both were required to enhance health.”<sup>52</sup>

An APHA in our study characterized how her experience living with HIV has represented a return to “the real me.” Another shared how HIV changed her “whole life” for the better bringing her to the realization that, “I wanted to live longer.” Rather than the shattered meaning and initial crippling response described earlier, several participants described how focussing on their health replaced the destructive coping mechanisms that led to the HIV infection in the first place.

*Since I was diagnosed it really woke me up. It scared me ... I know alcohol doesn't help with our problems, our health. It'll only make it worse. So for me when I was diagnosed, I just completely stopped drinking because I wanted to focus on my health. This is how much I care about me. As a drinker I wouldn't care, but now that I don't drink, I do care about a lot of people that are around me.*

**Molly, Inuit PHA**

*Actually, this might sound crazy but, once I became HIV-positive, it's just like everything ... I left my old life behind. And I tried to change my life around, and straighten out my life for one thing, stay off drugs, find out about my culture and things like that.*

**Wanda, Métis PHA**

### **3.4.3 Human Connectedness: “Second Family”**

Following an HIV-positive or AIDS diagnosis, “human connectedness” and a “sense of belonging” have proven to be crucial elements in learning to cope and live with HIV/AIDS.<sup>53</sup> This generally occurs on two levels: social connections with a larger community, and emotional connections with family and friends. Among the APHA study group, strategies for establishing

<sup>52</sup> Barroso and Powell-Cope 2000:347–348.

<sup>53</sup> Barroso and Powell-Cope 2000:345–346.

human connectedness included volunteering at HIV drop-ins and Native Friendship Centres; joining support groups such as talking circles; becoming active members of local, regional, and national Aboriginal AIDS organizations; learning speaking skills in order to inform Aboriginal students about the risks of HIV/AIDS; and accepting help from others, especially family and friends. For example, getting involved in Aboriginal AIDS networks at the regional (and later at the national) level, strengthened Arlene's connection to the Aboriginal community — particularly to other Aboriginal women. Her work with these organizations was nationally recognized and she was considered a leader in the movement for greater attention to Aboriginal women's' issues in the field of HIV/AIDS.

*I'd rather be working on the Aboriginal side ... The first reason why I came to [the regional Aboriginal AIDS Network] is to hunt out women with HIV and AIDS, and [find out] why they don't join these organizations. Or why they're afraid to tell people, their families ... why they have AIDS ... Being an Aboriginal and a woman and ... I just felt I needed to be helping with my own community ... More important to me was for me to find out why women don't say anything. Because when they go out there, when they find out they're [HIV-positive], they're either known as gay, because they have this disease, or they're sex trade workers, you know?*

**Arlene, First Nations PHA**

For many participants, strategies for establishing human connection entailed principles of reciprocity and becoming meaningfully involved in an effort to connect not only with others but to keep busy, productive and creative. One APHA said that helping others was her way to “keep my mind away from this illness.” Meaningful engagement in AIDS or other work can enhance well-being, including improved mental health and self-esteem.<sup>54</sup> Marc volunteers every day at a Native Friendship Centre and regularly at a homeless shelter because “it keeps me busy.” For Owen, volunteering at an AIDS organization is a source of self-esteem and capacity building, and provides him with personal support in his healing journey. For others, like Molly, volunteering is a way to keep busy and “away from drugs and alcohol.” For these and other APHAs who have become active in providing social and support services as volunteers, such commitments are a source of pride and purpose and a deep sense of belonging. In the majority of cases, APHAs have sought Aboriginal-specific agencies such as Native Friendship Centres (some of which have HIV/AIDS programming) or community health centres (some of which have Aboriginal programming).

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<sup>54</sup> Ontario HIV Treatment Network 2007.

*Well, the way I look at things, I don't let that illness bother me one bit. It's like as if I don't have it. I know it's there. I don't think about it. I only think about what I do everyday just to stay alive and keep my health going and get involved in activities, exercise or work. Whatever keeps my mind away from this illness. I know I have it. I don't think about it. The more I think about it the more it's going to do more harm to myself ... I don't think negative. I think positive all the time. Because I do a lot of things — I do beadwork, I do drawings, I do batik ... I got so many things to do. I do handicrafts, beadwork and stuff like that. That's what keeps me going all the time.*

**Orville, First Nations PHA**

An inner-city HIV health centre that integrates social, medical and support services under one roof has also developed a strong Aboriginal program including access to sweat lodges and other healing ceremonies. APHAs spoke highly of the opportunities to learn and to give back, and about the importance of the “second family” they have found at this centre. Walter volunteered “thousands of hours” there and encouraged other Aboriginal PHAs to access their services: “They helped me, and I thought for a while I was beyond help. If primary health care can be like this everywhere, we'd be basically solving a lot of problems and we'd be making a lot of people's lives better.” Wanda volunteered at this same centre because it is important “to help other people” and because it “keeps me busy! Keeps my mind off of dope!” Wayne also spoke about the importance “to get up and out and do something” and identified volunteering at this HIV health centre as providing a main pathway on his healing journey.

As discussed earlier, many APHAs decided to leave their home communities and move to urban areas, or to stay in an urban area rather than return home when diagnosed. Community-based support professionals commonly spoke about the importance of PHAs finding “a sense of family” among peers and “a sense of home” at HIV support agencies. “Family” is re-defined in more flexible terms, perhaps to include “the three or four people on the street who you really trust for a whole lot of reasons.” A few support workers believed that finding a sense of family and a safe space was of particular importance to their Aboriginal clients who were a long way from their home communities with limited options to return.

*I find one thing that is unique about APHAs that we see in the [drop-in] is a strong need and desire for the peer-support model. And I find we're lucky to have a space where we can provide that. And because of the space we do have, we can really see those interactions going on — the sharing of stories or experiences ... I find that APHAs really seek out that peer support. I think some of that stems from the fact that because we are located in a city, that some of the APHAs probably feel very isolated ... So I think that really gives a sense of home, and somewhere where they can relate. And relatively speaking from my experience, most people find it a safe space.*

**Service Provider: HIV drop-in support worker, ON**

The executive directors of two Aboriginal ASOs located in different parts of Canada emphasized that finding family and safety is critical to APHAs' healing journeys. They emphasized the need for programs and services that "will work with individuals in the long term, and help them live with HIV." Because the "reality for our people is often a lack of any supportive family," APHAs reach out to find other family. These executive directors agreed that what often happens is that ASO staff become part of APHAs' lives. They added that long-term funding is needed to not only provide that level of relational care, but also to create and integrate Aboriginal life/skills programming for young APHAs facing a lifetime of HIV/AIDS.

*I think once you teach APHAs coping skills, you really become a part of their lives ... We walk through almost all the processes with them when they first get diagnosed, when they're first into treatment, when they first decide that they want to start their treatment, planning for their death, how to prepare their families, how to talk to their family about being HIV-positive. So I think it becomes like you're their extended family. And I think that's what's different with Aboriginal service provision, is that we are like family. You will notice that, at our gatherings — that everybody is in such a tight community.*

**Service Provider: Aboriginal ASO staff, Atlantic**

APHAs living in urban areas and far from their home communities shared the importance of Aboriginal staff and peers to their healing journeys. For Mary, who described herself as "very shy" and who had difficulty trusting others with information about her HIV status, the fact that her support group is Aboriginal is important "because they're comfortable ... like a group like brothers and sisters." Molly repeatedly emphasized the importance of the Aboriginal HIV worker at the Native Friendship Centre who she visited, especially when "I'm down or depressed" because "I have a lot of trust in her." Max also found "great moral support" from an Aboriginal HIV worker at the Native Friendship Centre. When Arlene discovered that other Aboriginal women were also affected by HIV/AIDS, she finally felt she "wasn't the only one out there."

A few APHAs said that Aboriginal HIV-positive peers were important because their shared sense of humour provided relief, comfort and commonality. Staff at an Aboriginal ASO view humour, laughter and joking as an important way of communicating with APHAs, as well as a form of healing. They recognized APHAs' sense of humour as a manifestation of their "resilience" in coping with the everyday trauma of living with HIV/AIDS. One Aboriginal HIV worker explained that, "In our culture, a lot of it is humour. A lot of it is poking fun at each other, but not putting each other down. That makes a lot of difference. And that makes it easier for them to open up to me, too." A non-Aboriginal nurse at an inner-city HIV clinic has also found humour to be an effective means of "being real" with her Aboriginal patients. Other studies have documented the

significance of humour (described as “dry exaggeration”) as a culturally appropriate and “useful tool to foster connections” between Aboriginal clients and health care professionals providing HIV counselling and testing.<sup>55</sup>

*The Native people I hang around with here who are HIV-positive I can understand. I can relate where they're coming from because they grew up almost the same way as I was raised up. So how we joke around, we can laugh at the same thing, we joke around and you're building a new family. And I don't like feeling ... being isolated ... Just the Aboriginal — it doesn't matter what tribe you come from. I've been around the United States and Canada, and plus socializing with people who are from the Territories, and we still have the same laughter and the same identity, I guess. We have something in common: “Yeah, I know what you mean.”*

Owen, First Nations PHA

### 3.4.4 “Times of Peace”: Spiritual and Traditional Aboriginal Wellness

*They're looking for something. And they struggle with their identity. “Who am I?” “What's my purpose in life?” and “Why do I have HIV?” But I think once they're connected with their own spirituality, they get their own answers. And they know who they are. And knowing who you are is the most important.*

Service Provider: Aboriginal HIV nurse, MB

Among those APHAs who are seeking to reconnect with their cultural heritage, exploring traditional Aboriginal approaches to wellness is an important pathway toward that connection. Health care and support professionals generally agreed that traditional wellness approaches promote positive health outcomes. The executive director of an Aboriginal ASO suggested that “adherence means something different for someone who is Aboriginal” because they may want to include traditional wellness practices in a treatment regimen that conventionally does not account for periods of fasting, drinking herbal teas, or participating in other ceremonial activities that might interfere with medications. Relational care in this instance requires that the health care provider be willing to have a conversation with their Aboriginal patient: “I know that this is important to you, and this are why these are important to you too, so let's figure out a combined plan.”

Several APHAs and a number of physicians who participated in this study spoke about such conversations and the potential of bringing the medical and traditional systems together. For example, a doctor and nurse employed at an inner-city HIV clinic noted the benefits of Elder

<sup>55</sup> Bucharski et al. 2006:743.

counselling not only in coping with adherence to HIV medications, but also to achieve “times of peace.” In terms of adherence, the anti-retroviral regimen and its side effects requires a commitment on the part of PHAs that also means accepting the reality of HIV in their lives. In turn, this often leads to reflections about, “What got me into this?” Aboriginal PHAs can use traditional resources such as Elder counselling that, for some, is beneficial in terms of providing cultural and spiritual support to deal with root issues.

*One of the situations is, of course, people have multiple health issues that they're dealing with. So many of our clients have mental health issues as well. For example, we had a client living with both a mental illness — which gave the client voices that they heard and visions that were very distressful — and also HIV. So the work with the Elder, in this case, helped the client put the visions and dreams and hallucinations, many of them, in a spiritual context of meaning ... of what those meant. So they became less distressing for the client and therefore the client was able to consider taking on this additional bit of stress, of the HIV medications. It was one of the nicest combination effects because through working with the Elder, he was able to bring peace around some of the parts of the hallucinations or the visions the person was having, but also was able to encourage this individual to take some anti-psychotic medication when other things continued to cause a lot of distress. So that's an example of where the different systems really helped an individual take care of their health on several levels. But also of just having ... more “times of peace” for someone who had a lot of suffering.*

**Service Provider: HIV nurse, MB**

That traditional wellness practices have a beneficial effect was supported by numerous other medical and support professionals. An HIV housing coordinator reported that when APHAs connect with lodges and other types traditional healing agencies, it tends to “accelerate stabilization” in their lives because, in his opinion, “that feels firm to them, that feels solid, it has history.” Generally, service providers have observed that APHAs who explore and engage in traditional practices “seem to cope better with HIV/AIDS and with everyday life in general.”

Several APHAs were explicit about the healing benefits of traditional wellness practices. Orville described living with HIV as a constant battle, which is pacified through help from counselling with an Elder and participation in traditional ceremonies. Owen is hesitant about ARV regimens that involve “taking 28 pills” and is seeking healing along naturopathic and traditional paths: “I feel like I have a calling to go inside [the sweat lodge] again because I was brought up in my Native traditional ways and I stopped following my ways when I was 17.” For Mike, traditional teachings of the medicine wheel are healing in terms of coming to a more holistic

understanding of his illness. Annette regularly practices *smudging*<sup>56</sup> at home and participates in healing circles with other APHAs whenever possible, both of which she “found very therapeutic.” Allen believes that he would “be dead today” if it were not for Aboriginal traditions.

*I fight with this thing inside of me. Sometimes I go to an Elder to help me, or a sweat lodge — whatever I go to. And sometimes I go to [the HIV drop-in volunteer] because he knows a lot about that too. We get together, we talk about it and it helps. It really does help. If you put your mind and your heart to it, you will understand.*

**Orville, First Nations PHA**

Several service providers also observed that APHAs tend to choose a traditional road in later stages of their healing journey. A community outreach worker recalled three Aboriginal clients who for years accessed mainstream services in the city, “and it wasn’t until they were very ill in the late stage that they wanted to get back with an Elder and traditional healing. It wasn’t until they were very, very palliative that they were wanting traditional services.” The executive director of a mainstream urban HIV support agency said that in her experience, APHAs who embrace learning about traditional practices as a way to deal with issues of identity are usually among those who have lived with HIV for a longer period and have come to a place where they look for other things in life — a sense of pride, for example. She added that this sense of learning and journey is not exclusive to Aboriginal PHAs; other PHAs also come to a place in their lives where they “seek something more.”

An Aboriginal HIV nurse specialist identified traditional forms of support, including Elder counselling and cultural gatherings, as a “key factor” in an APHAs’ successful healing journeys. In her words: “There’s always a healing. Every time you go, there’s always a healing that comes out of that somehow . . . The cultural component, when it attaches to that person, I’ve always seen them moving forward.” An HIV specialist used these same words about the benefits of traditional healing, stating that “some Elders are very good with clients in terms of being able to reset the clock” through cleansing ceremonies and helping APHAs to “move forward” with their treatment.

Many of the APHAs in our study shared stories about the spiritual side of living with HIV/AIDS and the importance of engaging in traditional healing practices. While for a few APHAs learning about ceremonies and listening to Elders is Nation-specific (e.g., Ojibway and French Métis), for most it was a more inclusive Aboriginal experience. Having been disconnected from their home communities or families, some APHAs expressed the need for a sense of “belonging.” For example, when Walter left his non-Aboriginal home town, he sought out the Aboriginal

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<sup>56</sup> Many First Nations peoples practice cleansing ceremonies known as smudging. Smudging is based on the teaching that before a person can be healed they must be cleansed of any bad feelings, negative thoughts, bad spirits or negative energy — both physically and spiritually. This helps the healing to come through in a clear way, without being distorted by negativity. Commonly, smudging ceremonies involve the burning of sage, cedar or sweetgrass, taking the smoke in one’s hands and rubbing or brushing it over the body.



street-community in the city where he “found a closeness and a group of people that accepted me as being an Aboriginal . . . I belonged somewhere and I was with a group of people that accepted me.” After 20 years of identifying solely with the gay community, Oscar began looking for “who I am” and re-discovered his “Aboriginal self.”

As was the case with several APHAs in our study, Oscar now identifies himself as “two-spirited, instead of being gay.” When Murray was first introduced to the Native Friendship Centre, he felt an immediate connection with fellow Inuit and other Aboriginal peers, some of whom are also HIV-positive. Wilma — who was adopted by a non-Aboriginal family in the United States — reconnected with her Ojibway culture mainly through the community health centre that offers Aboriginal programming: “Knowing the answers” about her Aboriginal culture and history “makes me feel better about who I am.” Annette pursued traditional pathways of her Miqmaq culture because it “makes sense” to her and because she, too, feels a “connection” with Aboriginal approaches to healing and spirituality.

Service providers said that APHAs’ healing journeys were uniquely “more spiritual,” “more resilient” and more often guided by “HIV/AIDS as a teacher.” One HIV physician specifically noted a more holistic approach to coping with HIV/AIDS among his Aboriginal patients who “don’t forget about the spirit.” In his experience, the Aboriginal community is “quicker” to consider spiritual pathways as “opportunities for healing.” An educator in a sexual health clinic also said that APHAs demonstrate “more of the holistic types of coping” in terms of their willingness “to deal with some of their emotional stuff, their spiritual stuff.” Although the HIV nurse who works in the same clinic also believes that Aboriginal spiritualism has been “a very important part of some people’s ability to make sense of [HIV/AIDS],” she also observed a propensity toward “fatalism” or “acceptance of the Creator’s will.” When an APHA responds with, “Whatever will be, will be — I’m not going to fight it,” this attitude serves to “frustrate” her efforts to assist them in taking the steps toward wellness.

In the views of other support workers, all PHAs are trying to find some spiritual place in the sense that “there are no atheists in fox holes.” Despite the degree of commonality among people living with HIV/AIDS with regard to a spiritual journey, several service providers specifically described the resilience they observed among APHAs as a unique characteristic of their ability to cope with living with HIV/AIDS. A support worker noted that APHAs who participate in traditional healing practices and cultural activities are particularly “resilient.” Two HIV drop-in workers observed that APHAs’ resilience is also characterized by their willingness to share and be inclusive of others: “The Aboriginal community will encourage other people to participate in their activities or presentations . . . they are one of the communities that is most inclusive . . . The Aboriginal community is very open to having different people joining in . . . ‘This is our culture — get to know us before you judge us.’”

*I definitely know some positive [coping skills] that I've seen ... It's this resilience that I've seen. We've been talking about discrimination and racism ... and there's this resilience that I've witnessed. And also a resourcefulness ... When I talk with a lot of the APHAs that I'm working with, they are resourceful enough to know, "Well, this is what I've done in the past, this is what we could do now ..." So, there's this knowledge of knowing what services are available ... and also knowing about what's out there in their community that they can access for support.*

**Service Provider: HIV health centre social worker, MB**

*It seems that most of the clients that we've dealt with that are Aboriginal, have HIV and have trauma, are extremely resilient. What they've survived and how they've coped just blows me away. That is unique in terms of that particular population ... They have managed to develop a set of skills that have actually helped them through this whole process. And a sense of humour! I don't know what it is, but a lot of the guys that present themselves, we're all being serious and then they say, "Whatever!" Is it kind of a persona or part of their protection? I don't know, but it's certainly something I've seen that's common.*

**Service Provider: Aboriginal treatment centre program manager, ON**

### **3.4.5 Many Pathways: Recognizing Diversity**

Aboriginal service providers interviewed commonly made the point that it cannot be assumed that all APHAs are interested in traditional healing journeys. Indeed, a failure to recognize and respect diversity among Aboriginal PHAs is antithetical to relational care.

*Just because the person is Aboriginal, it doesn't mean they're traditional. It could be the Christian route, or the atheist route, or whatever it happens to be. You can't assume that just because they're Aboriginal that they're into traditional stuff.*

**Service Provider: Métis HIV support worker, MB**

Several APHAs do not participate in Aboriginal wellness practices because traditional spirituality is not part of their belief system. Wanda does not use alternative kinds of natural medicine and does not have confidence in traditional healers because she found it too "hokey." For Wendy, traditional practices such as burning sweet grass or participating in a sweat lodge "doesn't do anything for me." Wayne was simply not interested in traditional ceremonies and Wesley stated that he did not think he "could handle a sweat right now." Sam was raised to "follow the Christian road" and felt he did "not fit in" with traditional approaches to healing. Stella was also brought up on a Christian reserve and although she had heard about sweat lodges and other traditional activities, she stated she'd never attended and "I don't believe in them."

Like Sam and Stella, several other APHAs were raised in Christian families and reserves and now find that, even though they are interested in traditional Aboriginal practices, these are not accessible to them. Arlene said “We never did that in my home at all” and while she sometimes sought out an Elder for counselling, “we don’t have that many Elders in our community . . . [just] the odd few that hold the traditional way of life.” Sara participated in some traditional healing practices before she moved into the city for HIV treatment, but now “had no access to it.” For other APHAs, the issue was that they did not know Elders who understood HIV/AIDS.

*In terms of support, I feel at this point there are no Elders to ask who are knowledgeable. Maybe there are, but none have approached the APHA community — because they are so over-burdened with other spiritual aspects of the community wellness and stuff like that. For an individual to say, “I need support, I need to see an Elder,” that’s quite non-existent for me.*

**Max, First Nations PHA**

APHAs also revealed a degree of fear that affected their decisions to avoid traditional Aboriginal healing practices, including a fear of the unknown. APHAs who were never exposed to traditional practices and those who think they will be pressured to participate at a pace beyond their comfort level, are nervous about exploring these pathways. At Wendal’s first sweat lodge, the Elder performing the ceremony had not been informed that this was Wendal’s first time, nor that he had health issues that might be triggered by extreme heat. Wendal “freaked out in there because I couldn’t breathe,” and has refused to return since that experience. Walter, too, was initially fearful about traditional wellness practices because he “didn’t know anything about it.” However, with the guidance of an Aboriginal counsellor at the HIV health centre, he began to explore ways to combine traditional healing and western medicine in order to achieve better health outcomes. Although Winston was presently learning traditional practices that helped him to “relax” and to “take my mind off” illness or other problems, he was less open to trying traditional medicines.

## 4. RELATIONAL CARE: PROMOTING HEALING

APHAs who participated in our study described relational care as involving two main themes: connecting and relationships. Connecting refers to APHAs' perception that a safe environment is one in which they felt they could connect with care providers and that those providers could connect with them, where they were comfortable, important and cared for as a person, not as a disease. In many cases, this was reflected in an Aboriginal presence in primary health settings and community-based organizations. Relationships were conceptualized as the ways in which service providers interacted with APHAs, and how they negotiated the care, treatment and support appropriate to each situation.

Service provider participants emphasized that competency had many more components than just provision of culturally relevant skills and knowledge. Cultural constructs of care overlapped as primary health care and community-based support providers spoke in a single breath about various aspects of relational care, including relationships of power, trust and respect; awareness of the impact of colonialism on Aboriginal patients' interactions within the health care system; and attempts to help them overcome associated obstacles. Core elements of relational care were identified to include trust; rapport; respect for individuality; regard for Aboriginal and holistic approaches to well-being; flexibility and openness toward alternative, complementary and integrated care strategies; and willingness to relinquish expert status and learn about how better to meet the needs of Aboriginal PHAs.

*Because of the historical experience with, well, non-Aboriginal authorities — priests, or anyone can be thrown into that mix — there's a certain expectation that people are going to be judged and looked down upon. And I think that the best way through that is simply treating everyone with respect, demonstrating care and concern. Particularly in the work that I do with addictions, one just has to be very open, transparent. Or if there are expectations, be firm, fair ... It's about what I can do and what I can't do, and that fundamentally the real work is theirs, it's not mine. The life that they put together that's worth living is one that has to be meaningful to them, not to me. And to encourage that exploration on a personal level. So I tend to be pretty up-front about that and just very encouraging and positive about the things that can work for them. Doesn't matter what it is. So maybe that attitude comes across and I like to think that we get to a point where there's mutual respect in a working relationship, and trust ... If they're HIV-positive, in a non-punitive way, we talk about issues around their drug abuse. What triggered them? What were the people, the places, the things that set them up? What can we do to help them?*

**Service Provider: Physician, methadone clinic, SK**

## 4.1 MAKING CARE CONNECTIONS

As we stated at the beginning of this report, the root of relational care is connection, the link between all living things that in some Aboriginal philosophies is coined in the phrase *all my relations*. In connecting with health care and support, APHAs revealed the ways in which they could relate to physical, social, emotional and spiritual environments. Similarly, service providers shared their observations and experiences about how, when and why they were able to connect with their Aboriginal clients.

*We need to relate to somebody on a level that's more than professional. Because professional can only take you so far ... It really depends on who that person is, and where you meet them, and how you understand them. And how you understand the different techniques of "reading" somebody ... So, it's not that you have to know everything about where they came from, and their ancestry, it's having an idea that we can relate about something.*

**Service Provider: Aboriginal outreach worker, QC**

### 4.1.1 Physical Connection: Welcome!

*It would be a wigwam ... Eight sides. It would be 150 feet from one side to the other. There'd be a main level. Then there'd be three or four more levels above that. Open in the middle, but all along the side walls, working their way up, would be offices for the people that work there. The base floor would be the ceremonial area. Everybody would be welcome. On the floor would be the medicine wheel. And the four directions would be the floor colours. And I would use the four colours of the four races. Everybody would be welcome in that space, First Nations, Métis, Oriental people, Black people, white people. Everybody would be welcome. It doesn't matter what culture you came from. You would know that would be a safe place for you to go. It would house Aboriginal-specific supports and support mechanisms. The circles would be open to everybody. And there'd be regular circles, healing circles for people living with HIV and AIDS. And within the circles for people living with HIV and AIDS, also there'd be space for people living with cancer and other terminal illnesses. There'd be another circle for caregivers of people living with HIV and AIDS. There'd be other circles for caregivers that are looking after Aboriginal people living with HIV and AIDS, because that would be a specific thing. There would be circles for Aboriginal people living with HIV and AIDS because that would be a specific target that would have unique issues. There would be open circles for everybody else living with HIV and AIDS. And open circles for everybody else that are caregivers. There would be regular sweat lodge ceremonies, and there'd be a sweat lodge in the back. There would be health funds for people to be able to access to get the things that they need. There would be an advocacy program that would kick ass! They wouldn't dare to step in anybody's way and deny access to anything.*

**"Ideal care" as described by Allen, Métis PHA**

Physical connection refers to the sense of space and place where APHAs are welcomed, comfortable, relaxed, and safe. In their descriptions of “ideal care,” many APHAs in our study described physical spaces that felt “like home.” Generally, these were drop-in or other community-based centres with an unstructured atmosphere where APHAs could “hang out,” meet with peers, and engage in various activities like computer rooms, coffee and bannock cafes or food banks. Trust in the level of confidentiality within this environment was imperative. Among service providers, there was a desire to make “safe spaces” for Aboriginal PHAs as has been done for the gay/lesbian community. The executive director of a mainstream ASO in the Atlantic region specifically asked if there is “a symbol that would be immediately recognizable to APHAs that would signify this is a welcoming space, an Aboriginal safe space.”

For many APHAs, a physical connection was established with Aboriginal art or architecture, which immediately acknowledged they were welcome and respected in that space. Andrew, for example, felt an immediate connection to his HIV doctor’s office because there were medicine wheels, drums and other native crafts in the office. The “comfort” he felt when first walking through the office door was later reinforced by the physician’s knowledge of Aboriginal traditions and teachings, and his attitude that “you’re not a number when you walk in.” An Aboriginal community-based service provider also stressed the importance of their facility as a “non-clinical, welcoming place where you don’t have to stand in line and get a number” and that incorporates traditional Aboriginal design, plants and colour. On a grander scale, a few APHAs imagined their “ideal care” facility as one built on Aboriginal architectural designs such as the teepee, wigwam or medicine wheel, which incorporates natural features of Mother Earth and holds circular spaces for traditional ceremonies.

An important element of physical space is that it alleviates the burden of health work. The APHAs who described traditional Aboriginal structures also insisted that multiple services would be provided within a single holistic environment, including clinical, complementary/alternative and traditional therapies, counselling, palliative care, financial and nutritional support and support for APHAs’ families. Accessing care, treatment and support at a “one-stop” health centre was suggested by APHAs in all regions we visited. Wish lists included a centre that provides HIV testing and monitoring, dental, optometry, alternative/complementary therapies, counselling, peer support, spiritual support and housing. A few APHAs reported they have already found such a place, and that community-based health centres that integrate medical treatment and support service should serve as models of HIV/AIDS health care provision across Canada.

APHAs repeatedly suggested the value of or need for a drop-in type centre where they could “hang out” and where peer support was available whenever needed. Described as “a safe place to go,” drop-in centres provide a socially equal environment that is supportive and productive and offer APHAs an alternative to potentially high-risk behaviour such as “going to the bar.” Service providers recognized the value of a drop-in environment that precipitated PHAs creating their own communities in an open and safe place where they can connect without

necessarily having to commit to seeing a provider. The value of being able to connect to this type of space is that it allows APHAs and service providers to build relationships on terms defined by the APHAs. An ASO executive director observed that oftentimes APHAs came to their centre because they “just need to be here,” and that “our approach is not to prescribe what people need or want, but to show that we’re available.” Staff at an HIV health centre also told stories about Aboriginal clients coming merely to “visit,” unlike most non-Aboriginal clients who tend solely to “come in on business.”

*Our HIV drop-in tries to provide an environment of comfort where people can be casual, a space arranged like a living room and not a counsellor’s office, so that people are meeting on a peer level. For me that’s very effective in the Aboriginal community because here they don’t feel that power imbalance.*

**Service Provider: HIV drop-in support worker, ON**

#### **4.1.2 Social Connection: Whose Face Do I See?**

*I know he’s an Aboriginal person. It makes you feel like you’re talking to somebody part of the family. Like you know you can open up to him and stuff like that.*

**Wendal, First Nations PHA**

*What I liked about the Aboriginal community is that we can sit down in a room together, not saying anything, and feel perfectly comfortable. If you go anywhere else and sit down, and if you don’t say anything, there is something wrong with you. You can’t just sit there and say nothing.*

**Oscar, First Nations PHA**

Making a social connection is recognizing a familiar face; sharing a common experience; being with a friend, not an authority; and knowing that you are not alone. According to some APHA participants, the first face they see in care settings was critical to their experience. A substantial Aboriginal presence was seen as more welcoming and had the potential to enhance the responsiveness of some clients to the environment, which in turn may result in improved access to care. In other cases, having service providers who were themselves HIV-positive, was viewed as the foundation upon which some APHAs felt they could best relate. Relational care providers understood the stigma many APHAs face from within their own families and communities and the need for some to hide their HIV status from those closest to them. Service providers create a safe environment, culturally and otherwise, when they understand that for some Aboriginal clients, living with HIV is a lonely road, and they are sensitive to the additional need for trust, confidentiality and emotional support among these clients.

For APHAs, the importance of Aboriginal HIV/AIDS service providers depends on the type of service provided. Physical care by an expert in treatment for HIV/AIDS was more important than cultural identity of the practitioner. However, for emotional, spiritual and psychological care, a number of APHAs preferred Aboriginal caregivers because they felt more trusting, accepting and respectful, and communicated more easily with Aboriginal staff. For example, Arlene preferred clinics and ASOs that employ Aboriginal staff because “it’s easier to talk to people of your own kind.” A few APHAs also noted that Aboriginal staff that were more likely to be connected with Aboriginal traditions, communities, supports and resources thereby represent a broader and more appropriate avenue through which APHAs’ needs can be met.

*I don't think that I would have the type of rapport that I do with some of these people if I wasn't Aboriginal. I don't think I'd ever achieve it. I don't think I'd ever reach that level. Because I'm Aboriginal, I'm culturally aware of various traditions and that sort of thing ... It's just knowing ... the surroundings and [the city] and the community.*

**Service Provider: Methadone clinic coordinator, SK**

In terms of primary care, some APHAs preferred an Aboriginal doctor or nurse because it eliminated apprehensions about racism and because they believed that Aboriginal service providers would have an implicit understanding about their situation. Oliver specifically chose to be tested and treated at an Aboriginal Health Centre “because they deal specifically with Aboriginal people.” An HIV nurse observed that when APHAs walked into the infectious disease clinic and noticed a few other Aboriginal people, “there’s that instant connection.” Although in general, primary service providers respected and valued the presence of Aboriginal colleagues and their benefits for the health of APHAs, a few Aboriginal health professionals working in mainstream agencies suggested that culturally competent and relational care was needed throughout the agency, rather than solely relying on Aboriginal staff to work with Aboriginal clients.

*There's only been one — as far as I am aware of, anyway — one cultural competence workshop. One hour. So it's lacking, terribly. And I think because they've hired an Aboriginal nurse, an Aboriginal support worker and an Aboriginal outreach worker, they think they've done their part. “Let them handle it.” But no, the other staff need to also. There's more and more Aboriginal people becoming HIV-positive — I can't handle them all.*

**Service Provider: Aboriginal HIV nurse, MB**

HIV peer support was an equally important aspect of social connection. Oscar said that for him, the priority connection is an environment that is HIV-positive, and that an Aboriginal connection is secondary. Support from HIV-positive peers was considered by some as the ultimate form of



safety, although the best of both worlds is connecting with an Aboriginal person who is HIV-positive. In the end, however, “the common denominator” is HIV. The value of peers is that APHAs have daily or ongoing casual contact, in contrast to service providers with whom appointments are generally necessary. HIV-positive peers help provide information and assistance in each others’ health work. Oliver said the HIV drop-in has helped him “come to terms” with HIV because it is “knowing that you’re not alone.” HIV drop-ins used by APHAs in this study were repeatedly praised for the peer support they initiated and nurtured.

*A place to go for coffee, sit down, and talk, and think everything’s going to be okay. You’re not going to die alone. That’s what the drop-in is.*

**Oscar, First Nations PHA**

*It’s somewhere to go, where you know they’re in the same boat you are. Out in the street or out in other places you’re always on your guard to let people not know what you have. There still is a stigma about it, a very big one, actually.*

**Wayne, Métis PHA**

Relational care providers understand that formal counselling is not always appropriate or accessible to Aboriginal people. In such circumstances, providing resources for finding peer support can be a very necessary pathway to healing. An APHA who provides support to many of his peers spoke of the importance of “non-verbal” counselling: “Even to just say hello to somebody that has also disclosed to me. Just being out there knowing what they’re going through and what I went through. Words that are better not to be spoken.”

### **4.1.3 Emotional Connection: They Listen to Me**

Listening, sharing and sense of family are ingredients of emotional connection. Inasmuch as an Aboriginal presence within care environments was viewed as favourable by almost all APHA participants, creating and providing a safe emotional space was equally important. A common theme in APHAs’ stories about the drop-ins, community health centres or Native Friendship Centres they frequented was the strong emotional connection they had with HIV-positive peers who were “like my brothers and sisters,” and with staff to create “a little family.” Individuals who have been living with HIV/AIDS for years have developed strong attachments and a “close feeling” to both clients and staff at these centres where “everyone is on a first-name basis.”

*Some doctors, they don't see our point of views and we try to explain to them, "This medication that you've given us, it tears a person inside out, practically" ... I got better service in [another city] than here. They listened to me a lot better up there ... Here, when I ask for advice, for something that I need, I don't know if they ignore it or — they just walk away ... Because when I asked [my former doctor], he's right there and just listens right up to you: "Is there anything else you want to know before you leave?" I like these kinds of doctors — sits down and listens to you. [My current doctor], he's not like that. I don't know what his problem is ... I want a physician that I can relate to.*

**Orville, First Nations PHA**

*I don't know if I want to get that close to my doctor. I don't see him as a friend so I would say "no" to him. Unless I get another doctor that's there for me emotionally, then yeah, I'll talk to him. You know what I mean?*

**Odell, First Nations PHA**

From service providers' perspectives, emotional connection begins with taking the time to listen. An outreach nurse noted that APHAs are "storytellers, they need to explain and explain and explain before we get to the point." An Aboriginal HIV nurse shared that "a lot of listening has to happen on my part to get to know the individual" — in part because in her experience, "a lot of the Aboriginal clients are more needy." Attributing this high level of need directly to the residential school legacy, she expressed relational care in explicit terms: "Sometimes I feel they look to me as a parent."

*I listen differently when I have Aboriginal PHAs because there's a whole sort of cultural background that is attached to being Aboriginal. Sometimes it's about being adopted, being fostered, growing up on a reserve, having either been in a residential school or parents who have been in a residential school ... So I sort of listen for clues that might help me understand where the person's coming from, what the person's connections are, what their experiences might be. Which makes me ask related questions ... If the person is a non-Aboriginal PHA, all of that stuff is not relevant.*

**Service Provider: Métis HIV support worker, MB**

Listening creates a safe environment, particularly in clinical environments that are stressful for some APHAs. The stress is compounded when an APHAs' first language is an indigenous language (e.g., Inuktitut). Participants suggested health care providers who do not take the time to listen and who do not ensure comprehension by their patients threaten health outcomes with regard to poor adherence to treatment regimens among APHAs.

*Sometimes it's difficult to go there to understand what they're talking about. When I don't understand, I just miss my appointment. I don't want to show up because they're not going to explain properly what I want to know. And they don't explain properly what kind of medication I'm taking right now which [is] going in my system, you know — my blood or anything. Sometimes I decide not to show up to clinic because I'm going to have a hard time to understand them again. So when I really want to understand, I bring one of the workers from [the Native Friendship Centre] here with me so they can talk with them, explain to them properly and explain to me properly.*

**Mary, Inuit PHA**

*[My family doctor], he's excellent ... He's great! He understands what my problems are, and he takes time to listen. But with the other one, my HIV at [the hospital], he just checks your body. But he says I'm doing pretty good, so I get along with him, I guess.*

**Opal, First Nations PHA**

The emotional support APHAs received from service providers was often linked to the personal relationships they had established over time. For example, a non-Aboriginal social worker employed at an HIV health centre and who has worked with APHAs for 17 years has repeatedly been asked if she is Métis because APHAs sense “we have a connection.” Developing strong emotional relationships with care providers, most prevalent in community-based ASOs, provides a safe emotional environment for APHAs to learn about themselves and begin a journey of emotional healing. One of the benefits of this type of connection is that it provides opportunities for APHAs to give back to communities through sharing their experiences and advocating for others who have not begun that healing journey. Walter attributed his involvement at the community HIV health centre to having “built confidence in myself, and helped me feel good about myself.”

Support in the form of information was valued among all of the APHA participants. However, many recalled that they were not interested in HIV information when they were first diagnosed with HIV. Relational care and safety was ensured by care providers who tended to better understand and accommodate the emotional impact that might diminish an APHA's desire for, or uptake of, information upon initial diagnosis. For example, Annette shared that during her first visit to the HIV specialist after she was diagnosed, the most “amazing” thing for her was that the doctor “listened ... he knew all these emotional things, and he was holding my hand.”

#### 4.1.4 Spiritual Connection: Human Competence

Spiritual connection embraces the notions of acceptance, open-mindedness and human competence. Spiritual space celebrates diversity: race, gender, sexuality and diagnosis are meaningless. For APHAs this means acknowledging the diversity of the APHA population in terms of cultural background (First Nations, Métis, Inuit), personal experience (adoption, foster-care, urban, on-reserve, residential school) and sexual orientation (heterosexual, homosexual, bisexual, transsexual, two-spirit). APHAs in our study objected strongly to being lumped into a single category and advocated equal treatment for all, irrespective of race or culture: “HIV/AIDS has no face.”

Fundamental to making a spiritual connection were service providers characterized as “understanding,” “open-minded” and “dynamic.” An Aboriginal healing and wellness coordinator defined this kind of connection as a “personal energy” that emanates from some individuals who implicitly understand and accept diversity, HIV/AIDS and the need for comfort, safety and “a home-like feeling.”

*I think it should be representative of the true population, so if I was running this place, I would definitely want that ethnic diversity. And that's the bottom line: I believe in equality.*

**Warren, First Nations PHA**

*We try and be accountable, respectful of differences, all those things. So when we're working with every client we always approach it in that same way: what do you need and how can we support and empower you to make those choices? And choices are one of the values that we really respect and work with. So in that sense I would say we do try to be competent with regards to all different cultural needs and sensitivities. But at the same time I do think that there are ways that if you learn more about different issues, you can go even further and make it an even more welcoming space and make yourself even more available.*

**Service Provider: Youth agency educator, ON**

A number of non-Aboriginal service providers, particularly those working in community-based support organizations, asserted that race and ethnicity were not core issues in providing good care. Based on their experiences, what mattered was that they demonstrated an openness and willingness to listen to APHAs' stories, to be taught about what APHAs' ancestors experienced and to learn what is “real” for each APHA. A team of outreach nurses who work solely in a large inner-city area felt no reluctance on the part of Aboriginal clients to connect with them or their health services. They attributed this “easy friendship” to a recognition by clients that they were “open-minded, open to talk to them . . . and open to their culture.” Cultural competence

was defined by several primary and community-based service providers as “appreciating the diversity of expression of culture and identity within the Aboriginal community.” One physician stated that respecting and accommodating differences can impact on an APHA’s decisions around treatment and care that “cannot be approached in a stereotypical way.” An Aboriginal HIV nurse defined cultural competence as “not assuming anything” about Aboriginal PHAs.

Several primary caregivers simply insisted that being “human competent” was the reason they were able to connect with APHAs on a deeper level: “being open and being there for the people and listening to what they say, whether Native or non-Native.” An Aboriginal support worker also defined cultural competence as understanding APHAs “on a human level” — getting to know someone from any culture or background and having a sensitivity to figure out how to connect: “It’s being able to relate, that’s what it is, cultural competency.” The executive director of an Aboriginal ASO agreed: “It is important for people that are dealing with APHAs to understand that they are human, first of all.” It is then important for service providers to understand that APHAs are the way they are because of a range of historical, cultural and social factors.

Finally, a spiritual connection requires non-judgmental, respectful, dignified care on the part of both service providers and clients. Representatives of several ASOs who participated in our study enforce policies whereby staff and clients who make undignified comments are “taken to task” immediately. Those who refuse to behave in respectful ways are asked to leave the premises. Relational care “promotes dignity and self-esteem in culturally appropriate ways.”

*As soon as you walk in this place they accept you for who you are and not what you’ve done. They don’t condemn you.*

**Winona, First Nations PHA**

## **4.2 NEGOTIATING CARE RELATIONSHIPS**

*I think just being ... not categorized or something, being treated normally. They may have felt that you’re there just for specific HIV or whatever ... but not having that as the sole perspective being dwelled upon. It’s just that fact of being able to go some place and being able to identify with other people, that it just really puts it into perspective for me. And just being able to see faces and knowing that they’re there because they have the same thing I have. You know they are living and coping with it.*

**Oliver, First Nations PHA**

Relationships were perhaps the most critical to APHA participants' perceptions of culturally competent and safe care. In particular, having a personable and dependable relationship with service providers, whether they were Aboriginal or non-Aboriginal, was often reported as the most important component of care. APHAs talked about how meaningful one-on-one interactions and affirmative social encounters shaped their experience with health care facilities and service organizations. They also told stories that expressed a need to collaborate in their care, treatment and support, and to negotiate their relationships with service providers.

“Negotiating health care” is defined by Barroso and Powell-Cope as efforts by HIV/AIDS patients “to assume an active role in care.”<sup>57</sup> APHAs in our study recognized the need to not only take responsibility for their health, but also to be more than passive observers of their health care providers' treatment strategies. APHAs in our study often asserted a more active role in reaction to negative experiences in the health care system — for example, in clinics where APHAs felt they were viewed as a disease, not as an individual. APHAs also sought a more active role in responding to value judgements by providers that were dehumanizing — for example, when HIV practitioners brushed off APHAs' efforts to take time to talk or ignored language and comprehension barriers when prescribing treatment. APHAs attempted to negotiate health care by self-initiating searches for information from a variety of sources and discussing alternative and complementary therapies with primary medical and community-based support providers. The sum of APHAs' efforts and service providers' willingness to negotiate is a model of relational care that values holistic perspectives, options for integrated strategies of care, trust and respect, and mutual decision-making.

#### **4.2.1 Holistic Care (Love and Respect)**

A number of APHAs were explicit about the importance of a holistic approach. They sought it out and were critical of care providers who were closed to approaches that go beyond physical or medical care. Several related the holistic approach directly to wellness approaches in Aboriginal teachings. Implicitly, other APHAs alluded to the importance of a holistic approach by expressing sentiments, several APHAs said things such as wanting to be treated as “a person” — a “human being” “with a name” — and “HIV is more than a disease.” They spoke highly of clinical care that was “delicate,” “warm,” “compassionate,” “polite” and “respecting.”

Treating APHAs with compassion and respect created a relationship that ensured safety, particularly in clinical environments that are stressful for some APHAs. One service provider stated that “it's always about a relationship, building a trusting relationship regardless of skin colour and race and things... so [APHAs] feel safe enough to ask questions.” Service providers who acknowledged and helped APHAs address emotional, mental, social and physical needs engaged in relational care by encouraging APHAs to access a range of care and support for their whole well-being.

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<sup>57</sup> Barroso and Powell-Cope 2000: 348–349.

#### 4.2.1.1 *Respect is a Basic Human Right*

A holistic approach to health care and support begins with respect as a fundamental human right. In the opinion of most APHAs, it was “respect” that made a primary health clinic a “comfortable” place to access care. Examples of respect included “not asking too many questions . . . that are really none of their business,” being “greeted and treated like a human being,” or being “referred to by my name.” For instance, through the holistic care Walter received at a community HIV health centre, he has learned that “I may be an addict, whether I’m practising or recovering, but I’m a human being and I deserve to be treated with respect.”

*I had to dismiss one doctor and a nurse recently over the last year ... because they were laughing. I would visit them and then they would, the nurse and him together, they would laugh after my appointment. It was always this laughing going on.*

**Mike, Métis PHA**

Service providers engaged in relational care say that what is most important is respecting the individual, listening to their story and validating them. Acknowledging that an APHA “is a person first and not a disease” was a repeated message from service providers who work with street-involved clients. An HIV physician whose patients consist mainly of street-involved individuals said that being “competent” and “sensitive” meant constantly reminding himself that “you’re dealing with a human being, with a person.”

*When I give talks, I like to quote [a fellow doctor] ... He said that he had a prostitute with HIV in his office and when she left, she turned around and said to him, “Thank you for treating me like a person.” And often people are not treated like a person; even First Nations people who are living on reserves and are known to have an addiction problem are often treated like second-class citizens.*

**Service Provider: HIV physician, SK**

*Look at the individual as a person first ... they belong to someone. Treat them with the same respect and dignity that you would want a family member treated. Look at all the compartments of their lives that make them a whole person, not just the drug use or the prostitution or the HIV.*

**Service Provider: Community health outreach worker, ON**

#### 4.2.1.2 *Compassion for the Whole Person*

Holistic care is generally defined as an approach that shows compassion for the individual as a whole by considering physical, mental, social and spiritual contexts of an individual's well-being. There was a common view among APHAs that primary clinics and hospitals focus on disease rather than wellness, and on "the physical" (CD4 counts and viral loads) rather than the "whole person." Clinics and hospitals were described as "cold" (impersonal) and sometimes "racist." As described in the previous chapter, APHAs from all regions told stories of perceived discrimination at hospital emergency wards because it appeared Aboriginal patients were made to wait longer than other patients. There was also scepticism about the drug cocktails and some APHAs were "fearful" of the negative and long-term side effects and refused to begin drug regimens recommended by HIV specialists. APHAs' views on the biomedical approach ranged from outright distrust to resignation to full acceptance.

*[My doctor], she's warm and gentle and she's like really human ... She's quite busy but she's got all the few moments to share the warm side of being a human being.*

**Murray, Inuit PHA**

*There's so many little things a person can do to help the immune system. They can do nothing to the disease, but they can help themselves with their immune system. That's how I look at it. Which is totally opposite of any medical profession. Which is why I'm [in touch] with the Aboriginal community and HIV and AIDS, because they are taking the approach as a holistic healing, you see? And there is not any other community looking at it that way, that I know.*

**Oscar, First Nations PHA**

Relational care providers were identified by APHAs as caregivers who respected them as individuals and who practised a holistic approach to care that considered all of their needs. Some APHAs explained that holistic and relational care approaches were found only in the Aboriginal healing community. For example, Oliver said he believes there is a "huge impact" in traditional teachings that everything is connected, and that spiritual, mental and emotional health play "a major role" in his physical well-being. However, in his experience, mainstream medical professionals have discouraged him from holistic types of care and have refused to "advocate any of that, or that it's going to help your immune system or prevent you from getting sick."

Indeed, it was mainly Aboriginal HIV/AIDS service providers who spoke directly to the issue of a holistic approach and the importance of taking the time to relate to clients, thereby acknowledging that the person is more than their illness. Aboriginal service providers



illustrated holistic care with symbols such as the First Nations medicine wheel<sup>58</sup> and the Inuit *qulliq*,<sup>59</sup> but agreed that what mattered was a constructive model of “holistic living: working with people where they’re at.” One Aboriginal HIV nurse said that making a commitment to add “that personal touch” in caring for APHAs “means the world to them.” In her experience, providing personalized outreach had particular health benefits for those APHAs still struggling with addictions and leading chaotic lifestyles that often result in forgotten medical appointments. For this nurse, caregiving was more than physical treatment or following a drug regimen, it was a relationship.

*Most of my clientele are Aboriginal. Most of them use the services at the food bank. So I make a point of going out of the clinic and to them at the food bank ... being visible, and letting them know that “I’m here, if you need to talk to me, I’m available.” Whereas, you get the nurses that work here who don’t do that. I find I make myself more accessible. You don’t have to have an appointment to talk to me. I give out my direct line to my clients. If they need to talk, they can leave a message. I’ll call them, or I may give a time when it’s best for them to call ... And a lot of times I’ll stay after work just to make an extra phone call and say, “How are you today?” Remind them of their appointments. One of the difficulties they have, especially the ones that are struggling with substance abuse, is their life is so chaotic, they don’t know from one day to the other, “Okay, is that appointment today? Is it tomorrow, is it next week?” So I look at my schedule the day before and I call them and say, “Listen, I’m just reminding you that you have an appointment with me tomorrow.” So, that personal touch!*

**Service Provider: Aboriginal HIV nurse, MB**

*Culturally competent care to me would be trying to be very sensitive to whatever a lot of their needs would be. And hopefully I would ask what their needs would be. But I would just watch to see what their communication style was and I’d try to be sensitive to that. I’d try to be sensitive to language issues ... To their spiritual issues ... Maybe it’s just, “What’s important for you, around your being?”*

**Service Provider: HIV nurse, MB**

58 In First Nations spirituality, the medicine wheel represents harmony and connections. The wheel is divided into quadrants representing the four directions (east, west, north, south). The colours of each quadrant vary according to specific First Nations cultures. The medicine wheel is considered a major symbol of healthy and peaceful interaction among all living beings on Mother Earth.

59 The lighting of the *qulliq* (Inuit soapstone lamp) celebrates the return of the sun in the hope of prosperity and success. The cleansing of the *qulliq* represents the old year going out and, with new oil and new wick, hope for the future.

Non-Aboriginal primary care providers also commented that a distinctive characteristic of their Aboriginal clients was their active embrace of paradigms of Aboriginal healing that emphasize holistic growth and development. Although one physician said he tries to counsel in a way that is holistic for all clients, Aboriginal PHAs tend to respond more openly to conversations about healing on emotional and spiritual levels. An HIV nurse said that “typically I think there’s more of a spiritual element in my interactions with people who are First Nations, and more of a holistic approach to care” that include the use of alternatives therapies such as traditional wellness ceremonies. APHAs said they “liked” HIV doctors who acknowledged the mental, physical and emotional sides of living with HIV, in part because they encourage APHAs to “take a real look at myself” and to re-evaluate HIV as something to “live” with rather than a debilitating disease. An example of this approach was described by Mary, whose HIV nurse helped her to connect with the local Native Friendship Centre because “she explained to me that I had to start to get to know people with HIV and AIDS ... to not be by myself.”

Community-based support providers described a holistic model of care to include the economic and social realms of APHAs’ lives. In their practice, the link between addictions, physical infirmity, emotional issues, poverty and housing/homelessness meant assisting APHAs to connect to a variety of services in order to simply take care of the basics of life. An HIV housing coordinator explained that sometimes physical health is not a priority and HIV treatment is “so far down the road that it’s not even a concern at all” because APHAs may be more interested in “being fed and getting out of the rain.” An Aboriginal ASO director reiterated this point, adding that the government funding to ASOs does not address these issues: “It doesn’t really help people live with HIV/AIDS, it helps them slowly die.”

*We talk about HIV being only a symptom of many other things that are taking place in our community. HIV is not the problem, the problem is those other things that need to get dealt with. And with HIV and AIDS, we see addiction as being a main thing that needs to get looked at. And we don’t see services and programs in the urban settings that are really dealing effectively with the problem. You know, with treatment they still are only treating one person at a time. We see two, three generations of families struggling; we see two, three generations of one family that have HIV ... It’s not only just one person. We need to deal with the whole family, as a family unit. And again, the systems and the institutions are creating barriers for people to really have good service and programming to help them heal. And it’s not only about taking a pill. It’s a lot more than that ... A perfect example is our annual conference. We always open up our conferences and our workshops for people to share their lived experiences. Whether they have HIV/AIDS, Hepatitis C, or they’re struggling with an addiction or in recovery. And you see an Aboriginal person sharing that in their life they’re dealing with a lot of things that caused them to be HIV-positive.*

**Service Provider: Aboriginal ASO staff, SK**

## 4.2.2 Flexible and Integrated Care (Courage and Wisdom)

*Unfortunately with medical people, we tend to organize our lives according to our comfort zone. And sometimes you have to organize your life according to your clients' comfort zone.*

**Service Provider: HIV physician, SK**

*Sometimes my job is to get people as much information as I can ... and then you make your choice and we support that ... even if that choice is diametrically opposed to any choice I would have made.*

**Service Provider: HIV housing team leader, ON**

Relational care reflects a willingness on the part of service providers to regard individual differences by offering care options to APHAs and the courage to respect their priorities and support their decisions. At the same time, relational care providers seek to balance sometimes contradictory needs and administer wisdom in helping APHAs to integrate types of care such as Aboriginal traditional with western medical practices or HIV and addiction treatments.

### 4.2.2.1 Choices and Flexibility: Health Work

Consistent with a recent publication documenting the “health work” of people living with HIV/AIDS in Ontario<sup>60</sup>, service providers interviewed for our study indicate that APHAs' healing journeys require a lot of hard work. In order to maintain the necessary level of health work over a prolonged period of time — described as a “lifelong process” by one HIV nurse specialist — APHAs respond to those around them who provide support and encouragement. An HIV physician acknowledged that many clients at his downtown HIV clinic “are so weary of having run the system.” This same clinic helps prepare PHAs for treatment by “slowing it down” — repeating the basics of viral loads and CD4 counts because “the whole person needs time to process” the health work involved in undertaking a drug regimen that “you’re going to be on all your life. And that’s huge for people.” For APHAs who live in rural areas or on reserves, their health work requires long-distance trips to an urban centre to access an HIV specialist. In the Atlantic region and in Saskatchewan, for example, service providers report that APHAs must travel anywhere from two to five hours for regular appointments with their specialist. For many, the logistics of transportation and perhaps overnight accommodation are added issues. If a driver or companion is needed, the situation is complicated further by APHAs' concerns about confidentiality.

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<sup>60</sup> Bresalier et al. 2002.

*Staying alive — it's hard work sometimes ... The clients that I deal with, they don't want to disappoint their families. But they're working so hard, and ask, "What if I did stop taking the drugs, how are they going to feel? Because I'm going to die faster." But there are other ways that you can cope ... Talk to an Elder. Talk to me. Talk about anything that's going through your mind, because that's another form of releasing a lot of negativity that they're feeling. The guilty feeling of quitting [treatment] altogether. Yes, the drugs keep you alive, but at the same time you have to be able to deal with the side effects from these drugs, too. And you need the support for that.*

**Service Provider: Aboriginal HIV nurse, SK**

*We try to communicate to them that we are aware that they are being put through the system. And that the system itself can be incredibly exhausting and incredibly frustrating. Within that we try to address as much as we can here and do as much as we can for them as we're able to, on that particular day, at that particular moment. But we're not always able to do everything.*

**Service Provider: HIV physician, ON**

Health work often involves difficult choices requiring wisdom on the part of health care and support providers to determine an APHA's degree of readiness to commit to the demanding and exacting drug regimen and to deal with its sometimes disruptive side effects. Being ready to begin HIV treatment may mean deciding to first take care of other health and lifestyle issues such as dealing with addictions, accessing mental health care, or securing a permanent residence. An addictions treatment counsellor emphasized the importance of APHAs' readiness to deal with the daily life impacts of HIV treatment: "They have choices to make as to when do they want to start this? How's this going to work for them? Are they going in the direction where they can remain abstinent and not be back on the streets?" The wisdom to balance the specific needs of each individual with the general needs of Aboriginal communities and cultures was raised as an issue by primary service providers as a group. For example, the tension between patient safety and cultural safety was evident among primary care professionals who found themselves in a position where culturally appropriate treatment might compromise an APHA's individual needs.

*It's really a mixed bag, too, in terms of where they live. Some people do better on reserve, [with] family support, cultural resources. And it's worse and they're at higher risk when they come into the city. Conversely, other people just don't feel that they have the resources and the support on reserve and they're better off in the city. So ... it's highly individualized. Culture definitely plays a role, but it varies from person to person.*

**Service Provider: Physician, methadone clinic, SK**

For several primary care providers, relational care meant delivering services that considered “where a patient is coming from” in terms of social concerns, past experiences and level of trust in the mainstream medical system — all of which were critical to an APHA’s readiness to begin anti-retroviral (ARV) treatment or adherence. In the words of an HIV nurse, “If they don’t buy in, it won’t work. You have to start with them and build your care around them.” For some APHAs who decide to begin HIV treatment, the act of taking pills on a regular daily schedule is in itself a difficult choice. The executive director of an Aboriginal ASO has known APHAs who, for disclosure reasons, kept all of their medications at work, took their pills from Monday to Friday but not on the weekend, or took the full day’s dose in the morning: “So the doctor tried to explain that this is not effective treatment. But because they didn’t want anybody to know . . . that was their way of trying to adhere to their treatment.” An HIV physician related a similar story of an APHA who lived and worked on his reserve, but because of an “anti-pill” (drug abstinence) attitude, decided to stop his HIV treatment: “So this guy quit all his pills . . . He’s hard to treat because he doesn’t want to take pills. He came very, very close to dying. He weighed less than 90 pounds the year when I started with him again.”

In order to support adherence among his Aboriginal patients, an HIV physician has wisely adapted his practice to “Indian time,” rescheduling clinics from morning to afternoon because many of his patients have addiction issues and “addicts don’t get up before noon.” For this doctor, developing a “therapeutic relationship” with his APHA patients is imperative to HIV treatment compliance. Nurse specialists who work with him have seen the benefits of this kind of flexibility with street-involved PHAs and with Aboriginal PHAs who require extra assistance to attend appointments, by driving clients back and forth to the clinic or making house calls when there is no other means of reaching them. The HIV nurse at this same clinic has accepted that many APHAs do not make appointments well: “You can’t knock your head against the wall and wish they would come. If they miss 10 appointments but keep phoning for another appointment, they get one. Even phoning for an appointment is a positive health step, so we try, wherever they’re at, to cheer them on.”

Flexible care was also demonstrated by primary care providers who informed APHAs about the full range of medical options they could offer, while at the same time assuring them that what and when they choose is their decision. In the words of an HIV nurse, “if they’re not ready to choose any piece we’ll still be there for them tomorrow . . . or in six months.” Staff at a sexual health clinic took the same approach with street-involved individuals for whom treatment was not an immediate option, “but we can help them deal with issues, so that maybe in a few years we can work with them on treatment if that’s what they choose.”

Several support service providers reflected on the philosophy of client-centeredness and of providing care that is individualized, fair, empathetic, inclusive and non-judgmental. They emphasized the importance of equality between service providers and APHAs, particularly in terms of ensuring that they did not dictate decisions but that decisions were made in

consultation with Aboriginal clients. A youth agency educator added that the courage to respect an APHA's choices came in large part from "knowing something about a person's culture and history," which, in turn, provides "insight into that person's choice or reactions to options."

At the same time, a few primary care providers suggested that negotiating a relationship with APHAs was a reciprocal process in which APHAs needed to take responsibility for and ownership of their well-being. In terms of health outcomes, HIV doctors and nurses considered this especially important in terms of APHAs being accountable for clinic appointments, either attending the appointment or calling ahead to cancel if need be. One Aboriginal HIV nurse said that follow-up work with APHAs is often a challenge because there is a failure by many to take "their own initiative" to return for care or support. For another Aboriginal nurse, negotiating health care is an opportunity to remind APHAs that anti-retrovirals allow them to "live" with HIV and to encourage them to develop life skills to pursue goals they had before they were diagnosed as HIV-positive.

*We work from a space that values individualized perspectives. So with all the youth that we work with, we're trying to keep our wit and trying to provide safety. And by safety I mean if you're HIV-positive, being culturally sensitive and so on. We try and be accountable, respectful of differences, all those things. So when we're working with every client, we always approach it in that same way. "What do you need?" and "How can we support you?" and "How can we empower you to make those choices?" And choices are one of the values that we really respect and work with.*

**Service Provider: Youth agency educator, ON**

Both medical and support service providers emphasized the importance of reaching a place of stability and permanence in an APHA's wellness journey. Support is essential for those APHAs who decide that HIV treatment is less of an immediate priority than dealing with homelessness or street involvement. An HIV drop-in counsellor explained: "I think that they're dealing with other things that are more important to them, perhaps, at that moment. Those basics need to be in place before they can concentrate on doing other things for themselves." The executive director of an Aboriginal ASO noted that "our communities are vulnerable" in every aspect of "social determinants of health," influencing how APHAs are able to care for themselves, how they can treat themselves and how they can get support.

*If they're living in a home where the windows are smashed out, or there's mould growing in the home, or there's no heat, then how are they going to take care of themselves? How are they going to be able to live a healthy life? ... We see that more so with Aboriginal PHAs than with other PHAs ... We don't have that luxury of saying, "Okay, now that I'm HIV-positive, I'm going to move to the city and I'm going to have all the support and care and treatment that I need." Because their family is at home.*

**Service Provider: Aboriginal ASO staff, Atlantic**

One of the options mentioned by all participants in our study is outreach health care. This was identified as necessary for those individuals — homeless APHAs, for example — who experience enormous difficulty adjusting to the health system, and for whom the health system seems unable or unwilling to accommodate. This applies also to APHAs who may be too ill to leave home to attend a doctor’s appointment. A handful of APHAs described their ideal care to include home visits by HIV physicians or nurses, or HIV outreach clinics in familiar environments such as Native Friendship Centres. In cities where HIV clinics are integrated with drop-in type centres, where APHAs congregate for social reasons or to access services such as food banks, APHAs value the comfort and security this option provides.

*Part of it has to do with process. If you’ve got to jump through a whole bunch of hoops to get there, people won’t jump. The priority that day just might not be getting to see the doctor. The priority might be feeding their kids, or whatever. And so you’ve got to make it as easy as you can for people. Pick them up if they need a ride, for example. It seems like such a small thing, but it’s a huge thing if you’ve got to walk across town, pushing a stroller with three toddlers.*

**Service Provider: HIV nurse, SK**

#### **4.2.2.2 Integrated Care: Traditional Wellness Practices**

A few primary care physicians and HIV specialists shared that in their practices, attunement with individual APHAs’ needs included a respect for and desire to work with Aboriginal approaches to health in an integrated fashion. This included instances when APHAs decide to follow a traditional medicine route and refuse the medical HIV regimen, and the HIV clinic responds by supporting that decision and offering to monitor their physiological reactions. Allen, for example, spoke highly of his HIV specialist, in part because “he supports me 100 percent in traditional practices.” However, several physicians pointed out that there is insufficient information about how traditional medicines can be integrated with HIV drug regimens, an unfortunate situation considering the number of Aboriginal PHAs accessing their services.

*I can go five days without the meds, without starting to do the “kick start” ... [My HIV doctor] did the extra research on those drugs and got me my regimen for my drug therapy so that I’m on a regimen that I can fast on.*

**Allen, Métis PHA**

*I have in the past said to some, "Here's your test results. I'm not sure if you want to give this to your Elder to look at what's happening on your test results," so both the healer and I are sort of on the same page in terms of the diagnostics. We've done that in the past, and that seems to work out some of the communication pieces. Not that the healer and I are in discussion, but we go through the conduit of the client: "My doctor gave me this medication," or "He gave me these results, this is what he said he was a little bit concerned about. What do you think?" And that's how we've worked it out.*

**Service Provider: HIV physician, ON**

A physician who works part-time at an Aboriginal health centre described the value of direct and "open lines of communication" between medical doctor and traditional healer in providing the best of integrated care for APHAs. By considering the various pathways of healing being pursued by one APHA, the caregivers were able to complement each others' treatments and therapies. When that APHA passed away, the Elder "helped to close the circle, not only for the community, but for the provider as well." This physician's courage was rewarded with "good memories of that whole experience."

Although most primary service providers said they valued the integration of mainstream medical approaches and Aboriginal approaches, in practice they tended to express this value in terms of biomedical belief systems that allow for complementary therapies that will not conflict with ARV treatment: "Are they working with Elders? Are they using teas? Are there potential interactions for some of the medications?" To support an APHA who at times chooses to prioritize traditional wellness practices over biomedical treatment shows courage, because for the HIV physician, it demonstrates the APHA's lack of full acceptance of the value of that treatment.

*We do have one individual who I have spoken to quite a bit when he's come in and talked about the practices that he does ... the sweat lodge and ceremonies ... the fasting and all that. He is the only one I really know of who is using other sorts of methods to cope with his illness. And at times, he stopped his medication, but of course he's had to go back on it ... The problem is that if patients stop and start meds a lot, then they tend to develop more resistance in their virus because the virus is then exposed to lower levels ... So that's a concern with that practice. So we really do not encourage that. But you know, you can only do so much ... I must say that he has been fairly regular more recently, in terms of coming to clinic accepting our care.*

**Service Provider: HIV specialist, Atlantic**



### 4.2.2.3 Integrated Care: Addiction Treatment

Integrated care also applies to HIV and addiction treatment. Active addictions are a major obstacle to becoming adherent to HIV drug regimes, and half of the APHA participants in our study said addictions were a major factor in their struggle to live with HIV. As discussed in the previous chapter, intensified substance abuse was an initial coping strategy after diagnosis, or soon after diagnosis addictions had to be dealt with in order to begin ARV treatment. Service providers who manage to integrate addiction and HIV treatment are engaged in relational care. Indeed, Ward stated that combined treatment for his HIV and addictions would constitute “ideal care.”

*Once I was diagnosed, given my lifestyle, the meds they were also prescribing ... was wrong because they didn't evaluate me at that time, given my point of entry ... because of my lifestyle, alcohol, I was street-involved, I was a sex-trade worker on the side and stuff like that. So given all that, when I came into that office, they didn't take it into consideration. They didn't evaluate me to say, "Well, is he a good candidate in terms of compliance?" They just said, "Here!" And I just immediately went to the pharmacy and got it filled and took them. And then I had to stop it off because of alcohol ... There was nothing that sustained me for compliance issues. I was just told to get the [medication], whether I complied to them or not.*

**Max, First Nations PHA]**

For APHAs struggling with addictions and accustomed to life on the streets, attending to medical needs represents a major challenge to healing. APHAs reported difficulties with treatment adherence because they did “not care” about themselves when using drugs or alcohol, or because they knew that their addictive lifestyle precluded adherence to a strict drug regimen.

*It's a journey, learning to pull all the pieces together ... For a long time, people would go into addictions treatment and didn't dare reveal that they had HIV. Or they would deal with their HIV at an AIDS service organization but didn't feel they could talk about an addiction they had. So people had to compartmentalize all these different things. And I think that in terms of Aboriginal community response, you could hit it very lucky. You could get the right conjoint, but there is going to be that work that's going to happen. Because not everybody has got it figured out, how those things interweave and connect yet. But the disease will force us to learn that. Force those who don't know it to learn it, because it affects every aspect of our lives, and the more that you do get integrated care for all the things that you're struggling with, or the successes that you've had in life, the better the HIV care is.*

**Service Provider: HIV nurse, ON**

*The bottom line in treating HIV is the same thing as the bottom line in treating addiction. If you don't have compliance, you're lost. And the way in which you get compliance is if the client has developed a therapeutic relationship with the person providing treatment.*

**Service Provider: HIV physician, SK**

Addiction treatment programs that work with APHAs to coordinate medical care for HIV, and HIV clinics that assist APHAs to enter into addiction treatment programs, provide APHAs with choices for better health decisions. Addiction treatment providers and HIV care providers who participated in our study were in unanimous agreement that dealing with addiction problems and HIV at the same time is important because one without the other is guaranteed to fail. As exemplified by Max's experience above, APHAs find it impossible to adhere to the drug regimen either because they do not understand the interconnection between addictive behaviour and HIV treatment, or they do not have the support to deal with their addiction before they can start the regimen. Addiction treatment and HIV care providers also agreed that integrated approaches must recognize that APHAs dealing with addictions are often dealing with substantial trauma that must also be addressed.

*I'd either be high, be drunk, hung over, or just too lazy to get off my ass and walk over to the [HIV] clinic ... And then maybe about the third or fourth time I actually made it in. And that's another thing that changed — they actually helped me here in such a way, built confidence in myself, and helped me feel good about myself ... by supporting me as a person. "Yes, you do drugs, yes you drink, yes you can clean up. You've done it, you've shown you can do it, we support you, we're behind you. We'll do whatever we can to help you. You're not a bad person. You are just a human being who's addicted, and we can work with that." And they showed me an out, and by directing me to the right resources and with getting the proper support, I was able to kick the habit and stay clean. And I'm going on to 15 months of clean time now.*

**Walter, First Nations PHA**

### **4.2.3 Trusted Care (Honesty)**

*For me it's like, I trust in two or three people, that's it. But I don't go anywhere else or I don't ask for help.*

**Mary, Inuit PHA**

*This is why I speak with [the Aboriginal HIV worker]. She's my only one-on-one. I put a lot of trust in her and I trust her with my worries.*

**Molly, Inuit PHA**

For virtually all of the APHAs we spoke with, being able to trust a service provider was the dividing line between good and bad care. Trust is defined by both APHAs and service providers to include non-judgmental attitudes and behaviours, knowledge and capacity to understand issues around HIV/AIDS, sexual orientation and addictions, and comprehension of confidentiality and anonymity concerns. An HIV drop-in support worker said that APHAs will not reveal what barriers they face until rapport is established and APHAs “begin to reveal where they’re coming from . . . where the addiction stems from, or the mental health issues that they are facing, or the oppression and discrimination that they face on a daily basis.” For the Aboriginal HIV nurse quoted above who sometimes senses that APHAs look to her as a parent, relational care was both explicit and essential: “If they feel that they can trust you 100%, then they will start talking about all their individual issues.”

*There’s an inherent power that comes with being a support worker and somebody coming to ask for services. But I think that trying to minimize it as much as possible, so people feel that you are conversing and interacting with them at a peer level, as much as you can, is highly effective in getting through to the other person. And basically it really comes down to: “You tell me what your needs are, you tell me what you need support around, and we’ll make it work. I’m here because I may have certain resources that you’re unaware of, that you might want to get connected with. I’m not here telling you what to do.” . . . So it’s really about providing people with certain tools that they now have access to so that they can sustain themselves for a long period of time. You’re not coming up with a quick fix or a panacea for one day, a quick remedy for all your problems and go home now. I think it’s about: How do I form an ongoing relationship with this person, with the eventual goal of someone becoming self-sufficient, self-reliant and independent? And that’s the key thing. I find if I’m able to do that and create that, that is what works for me as a service provider in building that long-term relationship of trust and rapport.*

**Service Provider: HIV drop-in support worker, ON**

An HIV nurse shared that APHAs tend to talk about their coping strategies — traditional ceremonies or other complementary therapies — when they have a “comfort level” that is reached once a “relationship had developed between health care provider and patient.” Developing a bond of trust requires spending time with APHAs. A social worker in an HIV health centre observed that “the majority of my Aboriginal clients with HIV are the ones that come to me more than anybody else for one-on-one attention. They come and just sit in my office, talking about everything and anything . . . they’re very trusting to tell me a lot of things.”

*There's a man who came to me last year and he told me, "I've watched you for the last nine months. And I realized that you're here to stay. So, because of that, I would like you to do a blood screening test for me." But he started with, "I watched you for nine months."*

**Service Provider: Outreach nurse, QC**

There was overwhelming agreement among participants — both primary medical and community-based support providers — that building this rapport “takes longer” with Aboriginal clients than with non-Aboriginal clients. Mainly this “longer process” of rapport-building was tied to an initial mistrust by APHAs of health and social service organizations, and apprehensions about being judged by those in authority. For example, an HIV nurse in the Atlantic region reported that “sometimes the person’s past experience in life and with health care in particular has interfered with our ability to develop a sense of trust, and it took a while to develop a sense of trust with the health care system.” An HIV physician has, over time, come to understand that he sometimes must allow Aboriginal patients time to respond to their HIV diagnosis. As well, his interactions with APHAs differ in terms of trust issues: “Gaining trust is generally a longer process than with other PHAs and I find I need to try to not come on too strong.” An HIV housing support worker sees this as a “cultural phenomenon” unique to APHAs, many of whom have come from a place of trauma, and hence they need time to “open that door” and enter into a trust relationship. Overall, health care providers acknowledged that working with APHAs meant needing to exercise “a little more patience” because building a rapport would likely “be a little bit slower.”

*Through my experience of working with different Aboriginal youth ... I found that it was really a matter of making myself available ... Often I found that they seem more resistant to connecting at first. Then once they connect, then we can start to really work. But there has been a bit more work in building that rapport ... With the Aboriginal youth, its going out of my way to try and create a space for them to feel comfortable speaking and joining and participating and engaging.*

**Service Provider: Youth agency educator, ON**

*In my experience, some people will tell us from the beginning where they're at, what community they're from and that sort of thing. And then other people won't. I find that in working with APHAs that it's a little harder to build that trust and it's a longer process. Definitely their Aboriginal identity does play a role in how I work with them — it impacts differently how we establish that relationship and how we work on things in that sense.*

**Service Provider: HIV drop-in support worker, ON**

Trust was also expressed as an important consideration when integrating traditional healing with medical treatment. Trust issues applied not only in terms of the viability of both approaches, but also in terms of the rapport and trust between the primary service provider

and the traditional caregiver. A physician who worked directly with a traditional healer at an Aboriginal health centre noted that the success of that partnership rested solely on their ability to trust each other and knowing that their distinct approaches would bring no harm to the APHA. APHAs also made it clear that no matter who provided care, they had to be honest, sensitive and trustworthy. Perceived and real lack or absence of trust erected immediate obstacles to APHAs' willingness to connect to home, family, traditional wellness or clinical treatment. APHAs frequently told stories about being afraid to go through the door of an HIV health centre because people who know them may identify them as HIV-positive before they are willing to self-disclose: "You're going to be called down and you're going to be told, 'You've got AIDS, that's why you're going there.'"

*And the healing parts in terms of the sweat lodges and doing ceremonies, those pieces have been really excellent in terms of, when it does happen, about connecting people. The unfortunate thing is it doesn't happen often. But ... the population that we're seeing sometimes make the decision to not connect to culture. Or not to connect to the home reserve. It's the disclosure piece that becomes the barrier to care, and the barrier to that connection ... Clients themselves have told me that they didn't trust to disclose the two-spirited part, or they didn't trust to disclose the HIV part, or they didn't trust to disclose the addiction part with their Elder because they're so afraid of the negative consequences that have happened to them in other sites. Or they may not have enough experience with an Elder to know that they're going to be judged — but they're not going to be judged. And like in any profession, there's good doctors and bad doctors, good nurses and bad nurses. And then there are some Elders that are better than other Elders. When trust has been such a big issue around disclosing, one comment can destroy an entire relationship. I've had that happen, where somebody's come back and felt judged by an Elder ... They label the entire experience around, "See, I should never have gone back to culture, I'm just being judged again. This is something I don't need right now in my life. I'm just going to focus on my health."*

**Service Provider: HIV physician, ON**

#### **4.2.4 Knowledgeable Care (Humility and Truth)**

*I have stumbled and screwed up several times along the way, but that is how I've learned. And I think again, going back to what I said, the best cultural competence is when you show an openness and willingness to learn and to grow and be big enough to acknowledge your mistakes ... What people appreciate the most is when you're able to humble yourself to say, "I don't know" ... We always think that we have to pretend to be the expert, but we don't.*

**Service Provider: HIV drop-in support worker, ON**

*The words, “I’m sorry, I screwed up, I’m sorry” are key, in my mind, to cultural competency.*

**Service Provider: HIV nurse, ON**

Relational care suggests that service providers are not always the experts. It demands a willingness and desire to learn about the contexts within which APHAs seek support or care, or both. Relational care providers make it their business to understand Aboriginal clients’ backgrounds of historic trauma, social, economic and logistical matters that affect how and where appropriate care, as well as resources to fulfil information and referral service requests, can be found for APHAs.

#### **4.2.4.1 Historical Knowledge**

Three HIV nurses — from Quebec, Ontario and Manitoba — independently concluded that being culturally competent meant “using your privilege to learn” about general issues of Aboriginal history and relations in Canada, without losing sight of individual APHAs’ differences. It also meant being genuinely interested in the cultures of their clients and eager to learn from them: “Don’t play a game that ‘I know.’ Admit you don’t know and ask your client to explain.” Support workers echoed these sentiments, adding that learning about the history of Aboriginal communities allows them to identify and understand systemic barriers and to help APHAs navigate what they perceive as authoritarian relationships in their health care journey. A drop-in support worker added that “the last thing they need now is to feel like there’s an expert telling them what to do, so I just tell them I’m hanging out.”

Because the service providers who agreed to participate in our study had generally provided long-term service to Aboriginal populations, they demonstrated a considerable degree of humility with regard to their own position in a colonial history and how that impacted their relationships with Aboriginal clients. For Aboriginal primary service providers, the discussion of colonialism was important in terms of understanding their clients and of change to the health care system. Among some non-Aboriginal support workers, the personal energy and commitment to providing care to Aboriginal peoples, and the desire to engage with Aboriginal communities, was viewed as a path toward learning relational care.

Despite this relatively high degree of self-reflection and knowledge among service providers in our study, staff working in Aboriginal ASOs expressed frustration at the general lack of education and relatively low knowledge level among mainstream service providers about Aboriginal people in the regions where they work. Aboriginal ASOs advocate for and work with the medical profession and mainstream support organizations to address education issues related to the diversity of Aboriginal communities in their regions, and the complex nature of issues faced by APHAs.

*I don't want to have to do an "Aboriginal 101" with them. I want them to understand us as Aboriginal people. I don't want to start telling them, "Quit treating us all the same." We're not all the same. We have different languages, we have different ways. Some of us have Christian beliefs and some of us have traditional beliefs. We don't all pray to the same person ... Some of our teachings should be respected by the medical profession and by other professions that we come into contact with. And we shouldn't have to always be the ones explaining why we need it this way, and that way. It should be known. So if you are providing services to Aboriginal people, then you better know the ways of Aboriginal people, and be respectful. Otherwise you're going to create a barrier and there's going to be mistrust, and there's not going to be good service in terms of programming for Aboriginal people who are struggling.*

**Service Provider: Aboriginal ASO staff, SK**

Unfortunately, not all service providers take the time to humbly reflect on the role they play in their patients' lives, and continue to project attitudes that leave APHAs feeling helpless and afraid. An Inuit PHA whose first language is Inuktitut had serious problems understanding her HIV physician but was "afraid to tell them I didn't understand" because, "they're doctors, you know, I'm just a normal [ordinary] person." The executive director of an HIV/AIDS support agency for women suggested that many doctors are invasive in their approach to Aboriginal women. As mentioned earlier, the perception is that doctors ask many more personal questions about Aboriginal women's sexual activity, number of children, or state of housing, than they would of non-Aboriginal women. Wanda, an APHA participant in our study, shared such an experience during an appointment with a locum physician who asked if she was a "hooker." Wanda then went to an advocate at the HIV health centre and together they confronted the doctor: "Why did you ask me if I was a hooker? Do you ask everybody that?" ASOs in most regions we visited provide advocates to all PHAs they serve, but many advocates related stories of the need to act as a liaison between Aboriginal PHAs and primary health care facilities such as infectious disease clinics. In the experience of one Aboriginal advocacy worker, this type of liaison "is not very easy," mainly because of "pompous" attitudes among some health professionals.

*I think that to provide competent, sensitive and efficient services to the Aboriginal community, you really have to have a very good understanding and knowledge and respect for the history of the Aboriginal community — in particular, the residential school system and the atrocities that were committed against the Aboriginal community — and how they were stripped of their language, culture, way of life, and values were imposed on them, religion was imposed on them — and the by-product of all of that are the addictions and the mental health issues and all the other barriers that people face.*

**Service Provider: Treatment centre program manager, ON**

#### **4.2.4.2 Cultural Resources Knowledge**

When asked to reflect on cultural issues of care as they relate to Aboriginal HIV/AIDS, medical and support service providers' responses reflected many elements of the original model of cultural competence: acquiring knowledge and a set of skills specific to Aboriginal clients. Conversely, community health outreach workers defined incompetent care as "not being aware or educated about what resources are available for APHAs." In the mind of an HIV housing support worker, it is "our business to know who's doing what, what's happening in the city in terms of Aboriginal programs, and who the players are."

APHAs appreciated service providers who knew enough about Aboriginal services available in the local area to be able to refer them to resources that might be more appropriate or accessible to them as a First Nations, Métis or Inuit person. For example, the HIV clinic where Sam and Sally were diagnosed was "supportive" because staff there referred them to an Aboriginal ASO where they could get information on the types of support available in the city. It was important to Oliver that the clinic where he was tested was able to redirect him to an Aboriginal health centre for medical appointments and to a Native Friendship Centre for traditional healing and wellness counselling.

Many mainstream service providers admitted that they "don't know enough" about how to care for needs specific to their Aboriginal clients. While they were generally willing to learn to provide more culturally competent services, they either did not know who or where to go to build such capacity, or they did not have the time or human resources to initiate Aboriginal culture-specific competency programs. However, several mainstream service providers have initiated relational care practices by "creating space" for Aboriginal traditional ceremonies, or for an Elders room, and by recognizing that there exist different cultural approaches to communication and personal interaction. The types of requests and recommendations put forward by service providers who participated in our study can be categorized as "immediate" and "long-term" resources.

#### ***Immediate Resources***

- 3 Information and clarification about access to services for off/on-reserve and Status/Non-Status Aboriginal clients:
  - written procedures and protocols for directing clients to services (especially basic services) to which they are entitled (e.g., housing, transportation);
  - facts about jurisdictional issues for assisting Aboriginal clients;
  - where to get help for APHAs going through the bureaucratic process for obtaining First Nations status (especially important with regard to non-insured health benefits); and
  - simple and brief fact sheets or booklets providing the above basic information.



- 3 Centralized access to Aboriginal resources:
  - Internet portal or email network accessible to local/regional service providers for information on Aboriginal-specific service provision (as outlined above);
  - local/regional contact person or agency where mainstream service providers can direct enquiries regarding Aboriginal service provision (e.g., Aboriginal ASOs such as Healing Our Nation [HON] in the Atlantic region, and All Nations Hope AIDS Network [ANHAN] in Saskatchewan are cited as excellent examples in fulfilling this mandate); and
  - Extend the reach of Aboriginal ASOs to medical facilities such as community health centres, doctors' clinics and hospitals (as suggested by primary service providers).
- 3 Up-to-date HIV/AIDS information that is easily accessible and culturally appropriate at a local/regional level:
  - AIDS 101 pamphlets, posters, etc., aimed at Aboriginal clientele within a specific culture and/or region (e.g., Miqmaq-Maliseet in the Atlantic region);
  - information about traditional Aboriginal service provision and healing practices, customized by region (e.g., interpretations of the medicine wheel); and
  - HIV/AIDS resources on the CAAN website.

### *Long-term Resources*

- 3 Community partnerships with Aboriginal organizations such as Aboriginal ASOs and Native Friendship Centres:
  - workshops, presentations and referral services by local Aboriginal organizations are viewed as a “best practice” in promoting cultural competence;
  - continuous cultural educational programs by local or regional Aboriginal organizations that include historical components (e.g., residential school impact) and address staff turnover;
  - sensitivity training to help service providers learn how Aboriginal clients want to be treated, and to create a “safe space” for clients in terms of the building (e.g., visual symbols) and personal comfort (e.g., communication and interaction);
  - models such as Healing Our Nations and All Nations HIV/AIDS Network, Aboriginal ASOs that keep mainstream service providers “culturally tuned” by cultivating productive partnerships in the Atlantic region and Saskatchewan, respectively;
  - Aboriginal services units in hospitals, such as those in Manitoba, and Aboriginal orientation courses mandated by health regions such as Saskatchewan, which are viewed as beneficial in building and maintaining cultural competency; and

- CAAN as an Aboriginal organization that, at the national level, could promote funding for “competence days” at mainstream ASOs (e.g., annual in-service training), and promote access to traditional services in regions where Aboriginal ASOs do not exist.
- 3 Outreach and mobilized services, aimed particularly at Aboriginal youth who are at-risk for HIV/AIDS:
- A major gap in providing services to APHAs, street-involved and at-risk persons is a lack of outreach or mobilized services. Many service providers report that “the reality of the streets” is that people are unable or unwilling to access institutionalized services (including ASO drop-in centres, etc.); several service providers view the lack of outreach as culturally incompetent service provision;
  - mobile services that include harm–reduction efforts, such as needle exchange, food, etc.];
  - vehicles which combine Aboriginal service providers (e.g., Native Friendship Centre) and mainstream service providers (e.g., ASO, sexual health clinic, needle exchange) and are cited as best practices (Montreal and Prince Albert both reported the benefits of this kind of partnership); and
  - peer outreach and advocacy, which could be useful for APHAs who have difficulty communicating with primary HIV/AIDS specialists.
- 3 Integration of addiction and infectious disease service provision to eliminate barriers:
- integrated methadone treatment, HIV/AIDS and Hep C testing and treatment at the same or nearby clinics. Many advocates feel referring a client to an infectious disease specialist at a hospital has a low compliance rate; if treatment could be accessed at the same or nearby location, many more Aboriginal and/or street-involved clients would comply.
- 3 Aboriginal service providers, who recommend:
- promoting “life–skills” programs for APHAs who are ready to “go on a healing journey,” including getting off disability;
  - motivating Aboriginal service providers to become educated about HIV/AIDS (e.g., promote partnerships between Native Friendship Centre staff and ASOs in the same city or region);
  - developing and supporting programs for Aboriginal ASO staff to “care for each other” (e.g., to avoid burnout); and
  - promoting cultural competency within Aboriginal ASOs with respect to diversity issues (sexual orientation, Status/Non-status, different cultural groups within a service area).

## 5. WISE PRACTICES FOR PROVIDING RELATIONAL CARE

In considering the health care experiences of Aboriginal people living with HIV/AIDS, we are reminded that although there are unique care, treatment and support issues related to HIV/AIDS, there are also challenges and barriers specifically related to being Aboriginal. Some of these barriers may be linguistic, others may be gender-based and some may be related to substance abuse or mental health issues. Stigma and discrimination certainly sets HIV/AIDS apart from other health issues, yet even before an Aboriginal person tests HIV-positive, they have likely had subtle negative experiences in the health care system that they cannot quite pinpoint. It is often a culmination of both tacit and explicit prejudicial treatment over a lifetime that taints their view of health care provision. All of these experiences contribute to reasons why some Aboriginal people chose not to initiate engagement in, or to disengage from, the health care system.

*The doctor I had before ... he was hesitant to give me certain drugs that I asked for. I was trying to tell him, "This is what works for me." And I found him kind of, just something weird about him. The way he acted with me. I can't put my finger on it but kind of like a prejudice, racist type of thing.*

**Wesley, First Nations PHA**

The following wise practices are based on the lived experiences found in the interviews that make up this study. It is our hope that these guidelines or wise practices help you to discover and nurture a shared vision of relational care — a kind of care that encourages a provider–client connection and relationship as the first order in meeting an Aboriginal person's needs and supporting their choices.

### 5.1 A LEGACY

A common assertion by some non-Aboriginal people is that Aboriginal people are living in the past. This assertion implies two false notions: the first is that Aboriginal people believe in a perfect world prior to European contact; the second is that the colonial legacy is a thing of the past that happened hundreds of years ago. It must be said that while Aboriginal people do not claim that utopia existed prior to European contact, they certainly do believe that Aboriginal societies were healthier in terms of their family life, social organization, culture, economy and spirituality.

Significant and steady change over generations — without sufficient time to respond to or mourn losses — has contributed to the social ills we observe in Aboriginal communities today. There has also remained a significant power imbalance, even within the last 50 years. It was

only in the late 1960s that Aboriginal people could vote. In the 1950s and 1960s, Inuit people were identified only by numbers assigned by the federal government. The last residential schools closed only in the late 1960s — and while not all survivors experienced abuse, many did and others witnessed it vicariously. Most First Nations, Inuit and Métis communities have survived policies of centralization, relocation and assimilation, the effects and forces of which are endured by the present generation.

**Wise Practice:** Acknowledge that many Aboriginal people wear the legacy of colonialism to varying degrees. Observe those who may more noticeably experience multiple challenges as a result of this legacy. Despite the challenges, many Aboriginal peoples take pride in their identity and demonstrate their values of survival and resilience in the face of challenges to their culture and health.

## 5.2 CULTURAL CONNECTION AND DISCONNECTION

Once seen as a strength, cultural and family connections have actually begun to show signs of being weakened in some health issues. The extended family system, in some cases, is beginning to show multiple HIV infections within its family units. This is due, in part, to values of sharing among family members — using one needle to share substances, for example. Aboriginal group and family members who have common interests such as injecting drug use tend to stay close to those with whom they share that commonality. Sadly, because needles get shared, when one person is HIV-positive and/or HCV-positive, there is an almost 100% increase in risk of infection for those second or third on the needle. Each time a needle is shared, a bit of blood from the person being injected goes into the syringe. Because the individuals are familiar and trusting with each other, the sharing relationship may prevent them from asking if anyone is HIV and/or HCV-positive.

**Wise Practice:** Approach Aboriginal families as a unit. In Aboriginal communities — urban or rural — it is not enough to provide education and information at an individual level. Ask direct questions about who shares needles. Offer to do home visits to show how to avoid risks by making needle exchanges available and installing sharps containers — and make the information available to everyone in the household.

## 5.3 LIVING WITH HIV/AIDS IN ABORIGINAL COMMUNITIES

Without a doubt, HIV infection or an AIDS diagnosis compounds issues being coped with on the individual, familial and communal level. Rather than labelling a family dysfunctional, it may be more useful to view them as related persons who are reacting normally to abnormal situations. For example, the residential school legacy has left intergenerational wounds in families where

grandparents or parents were taught as children that they must be “saved” or changed by a moral authority who then sexually or physically abused them.

Some APHAs who come from stronger family units may experience support and open acceptance. Others, who come from families that are outwardly showing struggles, may face rejection and further marginalization when HIV/AIDS becomes part of the equation.

**Wise Practice:** Health practitioners, chiefs, mayors, council members, elected and non-elected leaders, Elders and community members who want to create a safe environment and provide relational care should deliver a deliberate and sustained message normalizing HIV/AIDS to Aboriginal families and communities. Don't wait for HIV to infect a community, or ostracize someone with HIV or AIDS to solve the problem. The reality is that if community members hear others within the community speak only negatively about HIV/AIDS, there is an almost zero chance anyone in that community needing support or thinking about taking a test for HIV will ever step forward.

#### 5.4 RACISM AND PERCEIVED RACISM

Perception is often reality. Several non-Aboriginal health care professionals in our study told stories of Aboriginal clients who “pulled out the race card” when situations were not in their favour. Even when a health practitioner does not believe they have behaved in a racist way, many Aboriginal patients will interpret gestures and attitudes as prejudicial based on a lifetime of being treated differently. One APHA participant said she is often presumed to be on disability or social assistance and is seldom asked if she has a job or career. She felt that she was generally viewed as a non-productive member of society — that being Aboriginal meant being on welfare. A non-Aboriginal HIV nurse cautioned about the indiscriminate use of Aboriginal-specific symbols, such as the medicine wheel, because such an attitude may presume that all Aboriginal clients would relate to that specific type of imagery. Although intended as a sincere attempt to culturally connect with the patient, the effect may be to confirm in the APHAs' mind that what the care provider sees is an Aboriginal person, not someone asking for treatment or support.

Many Aboriginal people cannot specifically name racism, yet often leave feeling that they were not treated respectfully or equally. This relational care study shows that some service providers are likely reacting to substance abuse issues. Although statistics confirm that almost two-thirds of new HIV infections among Aboriginal people are due to injecting drug use, many Aboriginal people who may or may not be using substances sense they are immediately judged as “junkies.”

**Wise Practice:** Be acutely aware that many Aboriginal people have experienced racism and discrimination and do not presume that substance abuse is a factor in their lives. Make every effort to reduce the perception that because they are Aboriginal, substance abuse or social assistance is presumed to be part of their life. Recognize that each Aboriginal client comes from a unique background, and treat each client as an individual who has the capacity and right to make their own informed health

## 5.5 OVERCOMING BARRIERS

Many Aboriginal people wear multiple layers of identity. An Aboriginal person who walks through the doors of a service agency may identify as both Aboriginal and gay, or Aboriginal and female, or an Aboriginal who is living with HIV and also injects drugs.

Many APHAs present both lifestyle and disease issues, and they want care providers who are willing to be flexible and provide information so they can make their own choices about HIV treatment regimes.

**Wise Practice:** Treat the person and not the disease. Be willing to find ways to help APHAs overcome lifestyle and health barriers (e.g., integrate addiction treatment and HIV care). Encourage patients' participation in decision-making and honour APHAs' health choices. Show compassion for the whole person by allowing APHAs to reveal what they feel safe to reveal.

## 5.6 THE CATALYST AND CULTURE

Not all Aboriginal people have had the valuable experience of knowing their culture and traditional ways. Some were fostered or adopted into non-Aboriginal homes or permanently scarred from residential schooling. Some cannot speak their Aboriginal language. Others may have become aware of their Aboriginal roots only when their First Nations status was reinstated through Bill C-31. There are also individuals raised in their Aboriginal community who have drifted from their traditional roots and who, for various reasons, do not participate in ceremonies and wellness practices.

Notable in this and other studies is that many Aboriginal peoples who face a significant life-altering experience, such as being diagnosed with HIV or AIDS, speak of these experiences as a catalyst to seek a better path through involvement with their cultural heritage and traditional teachings and practices.

**Wise Practice:** Maintain a close working knowledge of Aboriginal-specific services in order to help APHAs who consider their HIV-positive diagnosis as a catalyst toward seeking a better path in life and health, particularly through reconnecting with their Aboriginal identity and culture. For referrals, contact knowledgeable Elders and Aboriginal organizations that provide discreet and confidential services. While confidentiality with any referral is always a concern, to best assist Aboriginal people facing a significant health issue, find support in as many places as possible.

## 5.7 SECOND FAMILY

As mentioned earlier, a traditional strength of almost all Aboriginal cultures is the extended family system. As well, an inherent quality of Aboriginal communities (urban or rural) is the ability to withstand and rise above multiple losses. Because Aboriginal cultures are, for the most part, family-based, the additional marginalization experienced due to one's sexual orientation, gender, substance abuse and HIV status increases the need for alternative connections when family and home community connections are not possible. Many individuals in this study spoke of the importance of a "second family" — connecting to people they meet at Native Friendship Centres, ASOs and other agencies.

**Wise Practice:** Create a safe space for APHAs to connect and support one another, one where they are assured of confidentiality and a non-judgmental atmosphere. Show understanding, and help APHAs who cannot be with their families of origin to find a "second family" that they can belong to who will walk with them on their healing journey.

## 5.8 MAKING CARE CONNECTIONS

As medical staff is stretched thinner and fewer doctors are available to serve growing numbers of patients, greater challenges exist for health care professionals to create quality connections and therapeutic relationships. As HIV is seen as an episodic illness in which PHAs shift from periods of physical strength to episodes of significant downturns in their health, support networks need to be well-rounded and provide connections on physical, social, emotional and spiritual levels.

APHAs in this study described what "ideal care" means to them in terms of physical attributes that would make their visit to a clinic more comfortable; social characteristics, including Aboriginal staff; cultural opportunities in the form of traditional wellness practices; or emotional supports in which service providers take the time to listen to whatever is going on in their lives at the moment. Of great importance to many APHAs' sense of ideal care was a spiritual connection in which they are treated with human compassion, and in which care providers — Aboriginal or not — were understanding and knowledgeable about living with HIV/AIDS.

**Wise Practice:** Take practical steps in care provision (e.g., allow a space within a facility where traditional Aboriginal wellness practices and ceremonies, such as smudging or Inuit *qulliq*, can take place). Work with Aboriginal agencies that have Elder services so that support can be obtained when needed. Acknowledge that many Aboriginal facilities are situated in poorer neighbourhoods yet fill an important role in the social fabric of a community. Support and expand these facilities with murals and other imagery to enhance the space and create positive images where Aboriginal clients feel good about entering and staying awhile.

## 5.9 NEGOTIATING CARE RELATIONSHIPS

It is impossible for a service provider to be aware of every facet of Aboriginal culture represented by clients who come through their doors. What is feasible is for a service provider to know that many Aboriginal people have shared histories that are often negative in their perceptions and experiences. Relational care providers recognize that even when an individual appears to be self-destructive, continued care must be provided to help ease the significant burdens they may carry through no fault of their own. How safe and cared for a person is made to feel is how well they will respond to the helping hand that is being extended.

**Wise Practice:** Express a genuine respect and trust for Aboriginal clients in providing care. Respect for the resilient nature of individuals, even when it's not obvious, is vital and the foundation of relational care.

## 5.10 CULTURAL RESOURCES

In order to fulfill these wise practices, service providers need both immediate and long-term cultural resources to further their learning and understanding, and to forge, maintain and strengthen connections and relationships. The lack of knowledge about basic health care issues that affect Aboriginal clients is a barrier to providing services to APHAs. As the executive director of a mainstream ASO stated, "We don't know how much we don't know."

**Wise Practice:** Aboriginal ASOs require long-term funding to provide mainstream service agencies and HIV clinics with cultural resources appropriate to their regions. Organizations should fund and accommodate access to Aboriginal, HIV/AIDS and educational resources. Staff should be flexible, develop new programs, and get to know their clients, communities, Aboriginal referral contacts and partners.



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# APPENDIX A

## APHA Sample Tables (n=35)

### A1. APHAs: Aboriginal Status

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Inuit	5	14.3	14.3	14.3
	Metis	8	22.9	22.9	37.1
	First Nation, status	20	57.1	57.1	94.3
	First Nation, no status	2	5.7	5.7	100.0
	<b>TOTAL</b>	<b>35</b>	<b>100.0</b>	<b>100.0</b>	

### A2. APHAs: Health Status

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	HIV+, no symptoms	16	45.7	45.7	45.7
	HIV+, minor problems	13	37.1	37.1	82.9
	AIDS, good health	3	8.6	8.6	91.4
	AIDS, minor problems	2	5.7	5.7	97.1
	Do not know	1	2.9	2.9	100.0
	<b>TOTAL</b>	<b>35</b>	<b>100.0</b>	<b>100.0</b>	

### A3. APHAs: Gender

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Male	19	54.3	54.3	54.3
	Female	15	42.9	42.9	97.1
	Transgender	1	2.9	2.9	100.0
	<b>TOTAL</b>	<b>35</b>	<b>100.0</b>	<b>100.0</b>	

#### A4. APHAs: Two-Spirit

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Yes	8	22.9	25.0	25.0
	No	19	54.3	59.4	84.4
	Do not know	1	2.9	3.1	87.5
	Do not understand	4	11.4	12.5	100.0
	<b>Total</b>	<b>32</b>	<b>91.4</b>	<b>100.0</b>	
	NR	3	8.6		
<b>TOTAL</b>		<b>35</b>	<b>100.0</b>		

#### A5. APHAs: Sexual Orientation

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Heterosexual	20	57.1	57.1	57.1
	Homosexual	8	22.9	22.9	80.0
	Bisexual	7	20.0	20.0	100.0
	<b>TOTAL</b>	<b>35</b>	<b>100.0</b>	<b>100.0</b>	

#### A6. APHAs: Age

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	19 or younger	1	2.9	3.0	3.0
	20-29 years	3	8.6	9.1	12.1
	30-39 years	9	25.7	27.3	39.4
	40-49 years	15	42.9	45.5	84.8
	50 or older	5	14.3	15.2	100.0
	<b>Total</b>	<b>33</b>	<b>94.3</b>	<b>100.0</b>	
	NR	2	5.7		
<b>TOTAL</b>		<b>35</b>	<b>100.0</b>		

### A7. APHAs: Settlement Type

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	City	32	91.4	91.4	91.4
	Town, Village, Hamlet	1	2.9	2.9	94.3
	Mobile (eg., City & Reserve)	2	5.7	5.7	100.0
	<b>TOTAL</b>	<b>35</b>	<b>100.0</b>	<b>100.0</b>	

### A8. APHAs: Transmission Mode

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Sexual contact	21	60.0	60.0	60.0
	Blood product/ contamination	1	2.9	2.9	62.9
	Sharing needles &/or other works	8	22.9	22.9	85.7
	Do not know	4	11.4	11.4	97.1
	Other	1	2.9	2.9	100.0
	<b>TOTAL</b>	<b>35</b>	<b>100.0</b>	<b>100.0</b>	

### A9. APHAs: Attended Residential School

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Yes	9	25.7	25.7	25.7
	No	26	74.3	74.3	100.0
	<b>TOTAL</b>	<b>35</b>	<b>100.0</b>	<b>100.0</b>	

### A10. APHAs: Years at Residential School

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Less than 1 year	1	2.9	16.7	16.7
	1 year	1	2.9	16.7	33.3
	6 years	1	2.9	16.7	50.0
	9 years	1	2.9	16.7	66.7
	10 years	1	2.9	16.7	83.3
	More than 10 years	1	2.9	16.7	100.0
	<b>Total</b>	<b>6</b>	<b>17.1</b>	<b>100.0</b>	
NA	25	71.4			
NR	4	11.4			
<b>Total</b>	<b>29</b>	<b>82.9</b>			
<b>TOTAL</b>	<b>35</b>	<b>100.0</b>			

### A11. APHAs: Mother &/or Father attended Residential School

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Neither Mother nor Father	16	45.7	45.7	45.7
	Either Mother or Father	10	28.6	28.6	74.3
	Both Mother & Father	2	5.7	5.7	80.0
	Do Not Know	5	14.3	14.3	94.3
	NR	2	5.7	5.7	100.0
<b>TOTAL</b>	<b>35</b>	<b>100.0</b>	<b>100.0</b>		

### A12. APHAs: Grandparent attended Residential School

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Yes	7	20.0	30.4	30.4
	No	8	22.9	34.8	65.2
	Do not know	8	22.9	34.8	100.0
	<b>Total</b>	<b>23</b>	<b>65.7</b>	<b>100.0</b>	
	NR	12	34.3		
<b>TOTAL</b>	<b>35</b>	<b>100.0</b>			

### A13. APHA attended Residential School \* Mother &/or Father attended Residential School (Crosstabulation)

Count

APHA		Mother &/or Father at RS					Total
		Neither Mother nor Father	Either Mother or Father	Both Mother & Father	Do Not Know	NR	
Residential School	Yes	5	2	1	1	0	9
	No	11	8	1	4	2	26
TOTAL		16	10	2	5	2	35

### A14. APHA attended Residential School \* Parent &/or Grandparent attended Residential School (Crosstabulation)

Count

APHA		Parent &/or Grandparent at RS					Total
		Neither Parent nor Grandparent	Either Parent or Grandparent	Both Parent & Grandparent	Do Not Know	NR	
Residential School	Yes	5	2	1	1	0	9
	No	9	7	4	4	2	26
TOTAL		14	9	5	5	2	35

### A15. APHAs: Affected by Residential School

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Yes	4	11.4	20.0	20.0
	No	14	40.0	70.0	90.0
	Do not know	2	5.7	10.0	100.0
	<b>Total</b>	<b>20</b>	<b>57.1</b>	<b>100.0</b>	
	NA	1	2.9		
	NR	14	40.0		
	<b>Total</b>	<b>15</b>	<b>42.9</b>		
<b>TOTAL</b>		<b>35</b>	<b>100.0</b>		

### A16. APHAs: Residential School Effects (MULTIPLE RESPONSE)

Category label	Code	Count	Pct of Responses	Pct of Cases
Addictions ('generational')	2	1	12.5	33.3
Unhealthy sexuality/Sexual abuse	4	2	25.0	66.7
High-risk choices/behaviour	5	1	12.5	33.3
Lack of parenting/skills	6	2	25.0	66.7
Loss of culture/language/identity	8	1	12.5	33.3
Family breakdown	9	1	12.5	33.3
<b>TOTAL RESPONSES</b>		<b>8</b>	<b>100.0</b>	<b>266.7</b>

*(32 missing cases; 3 valid cases)*

### A17. APHAs: Province/Territory

	Frequency	Percent	Valid Percent	Cumulative Percent
<b>Valid</b> Saskatchewan	5	14.3	14.3	14.3
Manitoba	12	34.3	34.3	48.6
Ontario	8	22.9	22.9	71.4
Québec	6	17.1	17.1	88.6
New-Brunswick	1	2.9	2.9	91.4
Prince Edward Island	1	2.9	2.9	94.3
Nova Scotia	1	2.9	2.9	97.1
Newfoundland and Labrador	1	2.9	2.9	100.0
<b>TOTAL</b>	<b>35</b>	<b>100.0</b>	<b>100.0</b>	

### A18. APHAs: Region

	Frequency	Percent	Valid Percent	Cumulative Percent
<b>Valid</b> Prairies	17	48.6	48.6	48.6
Central	14	40.0	40.0	88.6
Atlantic	4	11.4	11.4	100.0
<b>TOTAL</b>	<b>35</b>	<b>100.0</b>	<b>100.0</b>	

### A19. APHAs: Aboriginal Status \* Region (Crosstabulation)

Count

		Region			Total
		Prairies	Central	Atlantic	
Aboriginal Status	Inuit	0	5	0	5
	Metis	6	1	1	8
	First Nation, status	10	8	2	20
	First Nation, no status	1	0	1	2
	<b>TOTAL</b>	<b>17</b>	<b>14</b>	<b>4</b>	<b>35</b>

### A20. APHAs: Diagnosis Date

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1987	2	5.7	5.7	5.7
	1990	2	5.7	5.7	11.4
	1991	2	5.7	5.7	17.1
	1992	2	5.7	5.7	22.9
	1994	1	2.9	2.9	25.7
	1996	2	5.7	5.7	31.4
	1997	2	5.7	5.7	37.1
	1998	2	5.7	5.7	42.9
	1999	4	11.4	11.4	54.3
	2000	5	14.3	14.3	68.6
	2001	1	2.9	2.9	71.4
	2002	1	2.9	2.9	74.3
	2003	3	8.6	8.6	82.9
	2004	1	2.9	2.9	85.7
	2005	4	11.4	11.4	97.1
2006	1	2.9	2.9	100.0	
<b>TOTAL</b>	<b>35</b>	<b>100.0</b>	<b>100.0</b>		

### A21. APHAs: Age at Diagnosis

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	19 or younger	2	5.7	6.1	6.1
	20-29 years	14	40.0	42.4	48.5
	30-39 years	7	20.0	21.2	69.7
	40-49 years	9	25.7	27.3	97.0
	50 or older	1	2.9	3.0	100.0
	<b>Total</b>	<b>33</b>	<b>94.3</b>	<b>100.0</b>	
	NR	2	5.7		
<b>TOTAL</b>		<b>35</b>	<b>100.0</b>		

### A22. APHAs: Years Living with HIV

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Under 2 years	5	14.3	14.3	14.3
	2-5 years	6	17.1	17.1	31.4
	6-10 years	15	42.9	42.9	74.3
	More than 10 years	9	25.7	25.7	100.0
	<b>TOTAL</b>	<b>35</b>	<b>100.0</b>	<b>100.0</b>	



### A23. APHAs: Age \* Years Living with HIV (Crosstabulation)

Count

		Years Living with HIV				Total
		Under 2 years	2-5 years	6-10 years	More than 10 years	
Age	19 or younger	1	0	0	0	1
	20-29 years	2	0	1	0	3
	30-39 years	0	1	6	2	9
	40-49 years	2	3	3	7	15
	50 or older	0	2	3	0	5
	<b>TOTAL</b>	<b>5</b>	<b>6</b>	<b>13</b>	<b>9</b>	<b>33</b>

### A24. APHAs: Health Status \* Years Living with HIV (Crosstabulation)

Count

		Years Living with HIV				Total
		Under 2 years	2-5 years	6-10 years	More than 10 years	
Health Status	HIV+, no symptoms	2	3	7	4	16
	HIV+, minor problems	2	2	7	2	13
	AIDS, good health	0	1	0	2	3
	AIDS, minor problems	0	0	1	1	2
	Do not know	1	0	0	0	1
	<b>TOTAL</b>	<b>5</b>	<b>6</b>	<b>15</b>	<b>9</b>	<b>35</b>

## APPENDIX B

### Service Provider (SP) Sample Tables (n=52)

#### B1. SPs: Aboriginal Identity

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Aboriginal	18	34.6	34.6	34.6
	Non-Aboriginal	34	65.4	65.4	100.0
	TOTAL	52	100.0	100.0	

#### B2. SPs: Gender

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Male	11	21.2	21.2	21.2
	Female	38	73.1	73.1	94.2
	Other	3	5.8	5.8	100.0
	TOTAL	52	100.0	100.0	

#### B3. SPs: Age

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	20-29 years	8	15.4	15.4	15.4
	30-39 years	10	19.2	19.2	34.6
	40-49 years	18	34.6	34.6	69.2
	50 or older	16	30.8	30.8	100.0
	TOTAL	52	100.0	100.0	

#### B4. SPs: Service Environment

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Urban	38	73.1	73.1	73.1
	Town	1	1.9	1.9	75.0
	Mixed urban-rural	3	5.8	5.8	80.8
	Mixed & On Reserve	10	19.2	19.2	100.0
	<b>TOTAL</b>	<b>52</b>	<b>100.0</b>	<b>100.0</b>	

#### B5. SPs: Education Level

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	High School	3	5.8	5.8	5.8
	College diploma	12	23.1	23.1	28.8
	University degree	36	69.2	69.2	98.1
	Other	1	1.9	1.9	100.0
	<b>TOTAL</b>	<b>52</b>	<b>100.0</b>	<b>100.0</b>	

#### B6. SPs: Occupation

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	MD, HIV Specialist	5	9.6	9.6	9.6
	HIV Nurse-Practitioner	11	21.2	21.2	30.8
	Social-Support-Outreach Worker	11	21.2	21.2	51.9
	Addiction Program Manager	2	3.8	3.8	55.8
	ASO Executive Director	7	13.5	13.5	69.2
	ASO Staff-Board	8	15.4	15.4	84.6
	HIV Educator-Consultant	5	9.6	9.6	94.2
	Aboriginal-Wellness Program Coordinator	3	5.8	5.8	100.0
	<b>TOTAL</b>	<b>52</b>	<b>100.0</b>	<b>100.0</b>	

### B7. SPs by Agency Type

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	AASO	10	19.2	19.2	19.2
	ASO	17	32.7	32.7	51.9
	HIV-ID-Sexual Health Clinic	13	25.0	25.0	76.9
	Addiction-Methadone Treatment Centre	3	5.8	5.8	82.7
	Native Friendship Centre	4	7.7	7.7	90.4
	Youth Services Agency	1	1.9	1.9	92.3
	Community Health Centre	3	5.8	5.8	98.1
	HIV Housing-Hospice	1	1.9	1.9	100.0
	<b>TOTAL</b>	<b>52</b>	<b>100.0</b>	<b>100.0</b>	

### B8. Primary/Medical & Community-based/Support SPs

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Primary/Medical SPs	16	30.8	30.8	30.8
	Community-based/Support SPs	36	69.2	69.2	100.0
	<b>TOTAL</b>	<b>52</b>	<b>100.0</b>	<b>100.0</b>	

### B9. SPs: Years Experience Providing HIV/AIDS Services

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1 year or less	7	13.5	13.5	13.5
	2-5 years	9	17.3	17.3	30.8
	6-10 years	16	30.8	30.8	61.5
	11-15 years	6	11.5	11.5	73.1
	16-20 years	10	19.2	19.2	92.3
	Over 20 years	4	7.7	7.7	100.0
	<b>TOTAL</b>	<b>52</b>	<b>100.0</b>	<b>100.0</b>	

### B10. SPs: Years Experience Providing Services to Aboriginal PHAs

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1 year or less	7	13.5	15.2	15.2
	2-5 years	8	15.4	17.4	32.6
	6-10 years	14	26.9	30.4	63.0
	11-15 years	9	17.3	19.6	82.6
	16-20 years	8	15.4	17.4	100.0
	<b>Total</b>	<b>46</b>	<b>88.5</b>	<b>100.0</b>	
	NR	6	11.5		
<b>TOTAL</b>	<b>52</b>	<b>100.0</b>			

### B11. Percent of Clientele who are Aboriginal as self-reported by SPs

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Less than 10%	13	25.0	35.1	35.1
	10 - 25%	1	1.9	2.7	37.8
	25 - 50%	4	7.7	10.8	48.6
	50 - 75%	4	7.7	10.8	59.5
	75 - 90%	6	11.5	16.2	75.7
	90 - 100%	9	17.3	24.3	100.0
	<b>Total</b>	<b>37</b>	<b>71.2</b>	<b>100.0</b>	
NA	5	9.6			
NR	10	19.2			
<b>Total</b>	<b>15</b>	<b>28.8</b>			
<b>TOTAL</b>	<b>52</b>	<b>100.0</b>			

### B12. Number of APHA Clientele as self-reported by SPs

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Less than 5	4	7.7	44.4	44.4
	5 - 10	3	5.8	33.3	77.8
	10 - 20	1	1.9	11.1	88.9
	60 - 70	1	1.9	11.1	100.0
	<b>Total</b>	<b>9</b>	<b>17.3</b>	<b>100.0</b>	
	NA	33	63.5		
	NR	10	19.2		
	<b>Total</b>	<b>43</b>	<b>82.7</b>		
<b>TOTAL</b>	<b>52</b>	<b>100.0</b>			

### B13. SPs by Province/Territory

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Saskatchewan	10	19.2	19.2	19.2
	Manitoba	11	21.2	21.2	40.4
	Ontario	10	19.2	19.2	59.6
	Québec	3	5.8	5.8	65.4
	New-Brunswick	6	11.5	11.5	76.9
	Nova Scotia	12	23.1	23.1	100.0
	<b>TOTAL</b>	<b>52</b>	<b>100.0</b>	<b>100.0</b>	

### B14. SPs by Region

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Prairies	21	40.4	40.4	40.4
	Central	13	25.0	25.0	65.4
	Atlantic	18	34.6	34.6	100.0
	<b>TOTAL</b>	<b>52</b>	<b>100.0</b>	<b>100.0</b>	

### B15. SP Agency Type \* Aboriginal Status Crosstabulation

Count

		Aboriginal Status		Total
		Aboriginal	Non-Aboriginal	
Agency Type	AASO	9	1	10
	ASO	3	14	17
	HIV-ID Clinic	2	10	12
	Sexual Health Clinic	0	1	1
	Methadone Clinic	1	1	2
	Addiction Treatment Centre	1	0	1
	Native Friendship Centre	2	2	4
	Youth Services Agency	0	1	1
	Community Health Centre	0	3	3
	HIV Housing-Hospice	0	1	1
	<b>TOTAL</b>	<b>18</b>	<b>34</b>	<b>52</b>

### B16. Percent of APHA Clientele \* SP Region Crosstabulation

Count

		Region			Total
		Prairies	Central	Atlantic	
APHA Percent	Less than 10%	1	6	6	13
	10 - 25%	1	0	0	1
	25 - 50%	4	0	0	4
	50 - 75%	4	0	0	4
	75 - 90%	6	0	0	6
	90 - 100%	5	0	4	9
	<b>TOTAL</b>	<b>21</b>	<b>6</b>	<b>10</b>	<b>37</b>







**CANADIAN ABORIGINAL AIDS NETWORK**