ADDRESSING THE NEEDS OF YOUNG PEOPLE LIVING WITH
PERINATALLY-ACQUIRED HIV: PROMOTING HEALTH
THROUGH COMMUNITY-BASED RESEARCH

by

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Abstract

There is a need for community-based tertiary health promoting and risk reduction programs that target the unique psychosocial and developmental issues of adolescents living with HIV in Canada. In a climate of increased accountability, well designed and articulated planning and evaluation research is paramount to securing funding and delivering successful health and psychosocial programs in communities. This dissertation represents a case example whereby research was undertaken to support community action.

A qualitative community-based participatory research approach was undertaken to create a health promotion program model for adolescents living with perinatally-acquired HIV in British Columbia, Canada. This process involved a multi-step collaborative partnership process including HIV-infected young people, their family members, their healthcare and service providers, university researchers, and international experts. The major goals were to: collaboratively assess the needs of the adolescents living with HIV in BC; to examine existing evidence in the literature for potential application to program design; to consult with international experts in the field of adolescent HIV care; and to form successful partnerships with various community stakeholders. Methods included in-depth interviews, focus groups, planning committee meetings, and facilitator training sessions, involving over 50 stakeholders.

The results from the various chapters included in this dissertation provide an example of the complexity inherent in working with such a ‘hidden’ population of adolescents. They identify priority program needs for the local population of HIV-positive children which...
include targeting areas of HIV stigma, sexual health, and mental health in adolescence and beyond. They show that partnerships such as this are challenged by factors such as technical, socio-political, and ethical quagmires. Findings from international ‘experts’ demonstrate that services targeting this population require multifaceted strategies for successful programs and that further examination of stigma opens upon a world of silences with intricate functions and meanings.

This dissertation is one of the few existing published works that incorporates the use of community-based partnership research and program development with a population of adolescents living with perinatally-acquired HIV. Implementing interdisciplinary, creative and engaging health promoting research strategies is a step towards decreasing inequities through marrying knowledge generation and program development.
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List of Abbreviations

Adolescent Women and Children Programs: AWAC
Acquired Immune Deficiency Syndrome: AIDS
Canadian Hemophiliac Clinic Director’s Group: CHCDG
Canadian Pediatric AIDS Research Group CPARG
Central Nervous System CNS
Clean living, Empowerment and Results: CLEAR
Community-based Organizations: CBOs
Community-based Participatory Research: CBPR
Empowerment Youth Evaluation: EYE
Hemophilia Behavioural Intervention Evaluative Project: HBIIP
Highly Active Antiretroviral Therapy: HAART
HIV/AIDS Youth and Child Umbrella Program: HYCUP
Human Immunodeficiency Virus: HIV
Institutional Review Boards: IRBs
Oak Tree Clinic: OTC
Mother(Parent)-To-Child-Transmission: MTCT
Paediatric European Network for Treatment of AIDS: PENTA
Polymerase Chain Reaction: PCR
Positive Youth Outreach: PYO
Public Health Agency of Canada: PHAC
Special Projects of National Significance: SPNS
Teens Linked to Care: TLC
US Centre for Disease Control: CDC
US National Institute of Health: NIH
US Department of Health and Human Services: US DHHS
Voluntary Counseling and Testing: VCT
World Health Organization: WHO
Preface

In 1994, I sat on my dormitory floor at the University of Guelph and had a debate with my roommate. She was explaining a homework assignment in her first year Women’s Studies class. The professor had asked that students write a critical piece about a restaurant with a “Cowboy’s” Special (consisting of a double burger and fries) and a “Cowgirl’s” Special (consisting of a not-so-subtle salad). At the time I told my friend that if she wanted a hamburger to just order the Cowboy’s Special – clean and simple. What I did not realize is that this discussion had dislodged something in my mind that sent me on a distinct path towards where I find myself today, moving away from my meritocratic individualistic beliefs and towards an understanding of how collective norms influence worldviews, how we perceive ourselves, and how we are perceived and treated by others. From that moment onwards, I believe that I became a social researcher.

The second event in my life that I would like to highlight is the opportunity I had to live South of the Equator, particularly in Zimbabwe, a country I know to be amazingly rich (culturally, historically, and geographically) and undeniably riddled with conflict and glaring inequities. There, I witnessed the devastation that HIV/AIDS brought to many people and communities already struggling. At my work, people were absent for funerals almost every day of the week. In visiting neighbourhoods and hospices, I spoke with HIV-positive children who were clinging to a world that would not see them survive to be teenagers. From these experiences, I was motivated to turn my attention towards health research. This dissertation pays homage to those children and the millions like them.
The knowledge that I have gained from these experiences has taught me to approach my research and its participants with respect and with a goal of partnership. It has taught me to be critical of hegemony and the power of the ‘researcher’. I have learned that everyone is an ‘expert’ in their own right and as others have suggested, that knowledge is co-constructed and contextual, a verb rather than a noun. For these reasons among others I privilege self-reflection, empowerment, and action in my research. I sincerely hope that in the end, I will have contributed to a positive phenomenon through my academic work.
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Dedication

This dissertation is dedicated in loving memory of my father, Wayne Russell Fielden, (1944-2001). He continues to inspire me to work in the field of Public Health, as he did.
Co-Authorship Statement

The following chapters were co-authored by the following individuals:

- **Chapter 2:** Lori Sheckter, Gwen Chapman, Ariane Alimenti, John Forbes, Samuel Sheps, Susan Cadell, and James Frankish

- **Chapter 5:** Gwen Chapman, Samuel Sheps, and James Frankish

In all cases, the candidate took primary responsibility in identifying and designing the research program, performing the research and data analysis, and writing and revising the manuscripts. The research program and associated grant were lead and coordinated by the candidate. The research tools, diagrams, research scripts, reports, ethical application and documentation were all developed by the candidate.
Chapter 1: Introduction & Synopsis of the Literature

Introduction

Community-based participatory research (CBPR) in population health promotion has several aims, including bringing researchers, community groups, and members of populations affected by a health problem together to work collectively and collaboratively to identify, understand, and address concerns. It is particularly well suited to creating research relevant to vulnerable populations who often do not directly benefit from traditional research methodologies as well as groups who have been historically exploited by researchers. The overall goal of CBPR has been described by Lantz and colleagues (2005) as “both to increase knowledge and understanding of a given phenomenon… and to apply the knowledge gained to guide the development of interventions, policy, and social change aimed at improving the health of community members” (p. 4). My dissertation, informed by this collaborative and action-oriented research paradigm, moves through several stages of health promotion program development with and for a group of perinatally-infected HIV-positive adolescents in British Columbia (BC) who are part of an emerging international cohort maturing into adulthood.

The goal of my doctoral research work has been to establish the foundation for a successful community-based health promotion program for the small BC population of HIV-infected young people. Cross-cutting all phases in the research as described in the chapters of this dissertation is the construct of evidence-informed practice. The various chapters explore different types of evidence production and synthesis, combining the perspectives of the local
stakeholders with peer-reviewed literature and the knowledge of the ‘experts’. The process moves from proximal to distal, beginning with the children in the local BC context, extending outward to an international community of ‘experts’, and ultimately synthesizing the knowledge gleaned for use by the stakeholders at every stage. Each chapter uses a different approach to ‘knowing’: Chapter 2 illustrates a collaborative study design with various local stakeholders to identify program needs, Chapter 3 illustrates the complexity of co-constructing and applying knowledge through providing an overview of a multi-stage research and planning project including the development of a research partnership, Chapter 4 illustrates the gathering and synthesizing of literature to inform program design, Chapter 5 describes a systematic consultation with the ‘experts’ for direction regarding program administration, and Chapter 6 presents an interpretive analysis of empirical data from these ‘experts’ to examine how HIV stigma contributes to programs for adolescents living with HIV. The initial needs assessment (Chapter 2) with older children and adolescents in BC pointed to a gap in youth-specific programs for adolescents and young adults living with perinatally-acquired HIV. Therefore the overall research targets this adolescent population in the local BC context while drawing on knowledge (e.g., from literature and ‘experts’) generated in resource-rich countries to inform the community-based participatory research and community program planning processes.

The following introductory section begins by summarizing relevant background literature regarding young people living with perinatally-acquired HIV including clinical, developmental, psychosocial, and cultural issues affecting HIV-positive adolescents and their families. As young people with perinatally-acquired HIV can be classified as both young
people with chronic illness and ‘HIV-positive youth’, this section also discusses the overlap in characteristics and implications for service provision. The various settings where the research stages took place are also presented, namely clinical and community contexts. The literature assists in positioning this research in time and a socio-political space. The following sections provide an overview of the research gaps, purpose statement, the theoretical groundings, the role of the researcher, and summaries of the dissertation chapters. Because the research process bridges many sectors and disciplines, this section introduces the various stakeholders involved the research process including myself as the primary researcher, the children, their family members, their healthcare and social service providers, and ‘the experts’.

**Young People Living with Perinatally-acquired HIV**

HIV was first discovered in children in 1983 (Oleske et al., 1983). It can be acquired perinatally: in utero, during childbirth, or via an infected mother’s breast milk (Read, 2006). This Mother(Parent)-to-Child transmission (MTCT) is the major cause of pediatric HIV infection worldwide although infection may also occur via contaminated blood products or tissue, unsafe injection or incision practices, or child sexual abuse (Prendergast et al., 2007). Prior to adequate blood screening implementation in 1985, some children and youth who received blood or blood products, mostly hemophiliacs, were infected with HIV (Arnold et al., 2006; King et al., 1996). Hemophiliac children were the first major HIV-infected pediatric cohort to age into adolescence and adulthood. Now they are being joined by the group of long-term survivors of perinatally-acquired HIV.
Globally, the number of children living with HIV continues to increase steadily (UNAIDS, 2008). The overall risk of MTCT without intervention is 15-30% in Europe and the United States but rates are higher in resource poor regions such as 25-40% in Sub-Saharan Africa (Prendergast et al., 2007), thus demonstrating how perinatal HIV transmission is not only a behavioural issue but is also a global developmental and health inequity issue. With the advent of combination antiretroviral therapy and other medical advances in the mid-1990s, perinatal transmission of HIV has drastically decreased in Canada and other resource-rich countries (PHAC, 2007). In Canada, since the introduction of Highly Active Antiretroviral Therapy (HAART), perinatal HIV infection rates have decreased 75%, with a less than 1% infection rate among those mother-infant pairs receiving three or more antiretrovirals between 1997 and 2004 (Forbes et al., 2006). The implications of this combined with increasing rates of HIV infection in women of childbearing age (PHAC, 2007) are that an increasing number of HIV-uninfected children who are ‘HIV-affected’ as opposed to ‘HIV-infected’ are living with one or several HIV-infected family members. As of December 31, 2007, there were 64,800 positive HIV tests with information about age reported to the Public Health Agency of Canada (PHAC) (PHAC, 2008). Approximately 25% of these cases are among young people less than 29 years old. Of these, 517 were among children under 15 years, 908 were reported among youth aged 15 to 19 years, and 15,379 were among individuals aged 20 to 29 years. In the youngest age group, 63% of reported HIV infections were perinatally-acquired.

In HIV-infected children, European and American cohort studies have demonstrated decreased mortality and morbidity due to increased use of HAART in pediatric care.
(DeMartino et al., 2000; European Collaborative Study, 2001; Frederick et al., 2000; Gibb et al., 2003; Gortmaker et al., 2001; Thorne et al., 2002). Evidence from these studies highlights the heterogeneity of HIV-positive children as a population – in terms of demographic, clinical and psychosocial variables. These children are now surviving into adolescence and adulthood (Prendergast et al., 2007) bringing to light new challenges for service provision.

The Canadian Pediatric AIDS Research Group (CPARG) reports that 2580 infants were perinatally exposed to HIV between 1984 and 2007 in Canada (PHAC, 2008). For the 311 HIV-infected children followed by 21 HIV pediatric centres across Canada, the median age is 11.9 and 27 are older than 18 years (Alimenti et al., 2007). No child has died of HIV-related causes since 2000 (Alimenti et al., 2007). Between 1997 and 2007, there were 273 live births to HIV-positive women receiving prenatal care at the BC provincial tertiary care centre, the Oak Tree Clinic (Dr. J. Forbes, personal communication, October 21st, 2008). A quarter of these reported births were to Aboriginal women and almost half of the maternal population had acquired HIV through IV drug use (Gilgoff et al., 2006). In British Columbia, approximately 40 children currently live with an HIV infection acquired during infancy or childhood (Alimenti et al., 2003). Many of these children have already become adolescents and young adults (Alimenti et al., 2003; Fielden et al., 2006).

Although it is often difficult to disentangle one category from another, the following sections provide a brief overview of biopsychosocial factors influencing young people with perinatally-acquired HIV. This is followed by sections that compare the perinatal population
with two populations notably similar to young people living with perinatally-acquired HIV: children with chronic illness and young people with horizontal (behaviorally-acquired) HIV.

_Clinical Features_

HIV infection is detected either through use of antibody (e.g., ELISA) or HIV-DNA polymerase chain reaction (PCR) testing. The PCR test is more accurate for children under 18 months due to lingering maternal antibodies (NIH, 2008; PENTA, 2008). Without treatment, HIV-infected children in developing countries have a mortality rate of 45%-59% by two years of age, compared with 10-20% in Europe and the UK (Prendergast et al., 2007). In the UK for example, progression to AIDS has decreased by 50% and mortality by 80% since the advent of HAART (Gibb et al., 2003).

There are two main clinical profiles of perinatally-acquired HIV: rapid progressors and slow progressors. Rapid progressors present in the first month of life with failure to thrive, chronic diarrhea, encephalopathy, and other severe opportunistic infections (Prendergast et al., 2007). However, most pediatric HIV infections run a more chronic course and will often remain asymptomatic or present later with recurrent infections such as otitis media, sinusitis or some more serious infections such as meningitis or pneumonia (Prendergast et al., 2007). Neurodevelopmental abnormalities related to central nervous system (CNS) infections are a frequent complication of pediatric HIV infection and may lead to developmental delays and motor deficits (Civitello, 2006). Although rates of infection and disease progression have improved with HAART, there are also reports of toxicities that are being caused by long-term HAART use including mitochondrial toxicity, lypodystrophy, and metabolic abnormalities such as hyperlipidemia and hypertension (Zeichner & Read, 2006).
Clinical and immune status staging in children and adolescents has been established by the United States Centre of Disease Control (CDC, 1994) and the World Health Organization (WHO, 2007a). The WHO has a four clinical stage system of classification ranging from Stage I (asymptomatic or persistent generalized lymphadenopathy) to Stage IV (e.g., severe wasting and AIDS-defining Opportunistic Infections) (WHO, 2007a). The CDC classification is similar and includes classes N, A, B, and C with N being asymptomatic and C being severely symptomatic. Immune categories range from no suppression to severe suppression based on age and CD4 percentage (CDC, 1994; WHO, 2007a). In Canada, children with HIV infection are evenly distributed across all the clinical and immune categories (Alimenti et al., 2007). All infants with HIV infection are recommended to begin antiretroviral therapy immediately and infected children over one year of age will begin antiretroviral therapy depending on the immunological and clinical assessments (PENTA, 2008; NIH, 2008). The US National Institute of Health (NIH, 2008), the Pediatric European Network for Treatment of AIDS (PENTA, 2008), and the World Health Organization (WHO, 2007b) provide guidelines for the use of antiretroviral therapy in pediatric HIV infection.

**Developmental Features**

Because childhood and adolescence is a time of rapid growth and changes, physically, cognitively and socially, living with HIV has special challenges for young people. Young people in general will go through significant transitions such as reaching puberty, school graduations, leaving home, and beginning in the workforce. HIV-positive children and adolescents, like other children with chronic diseases will experience clinical transitions in their HIV care, as they shift from pediatric or family services to adolescent or adult health services (Miles et al., 2004; Thorne et al., 2002; Weiner et al., 2007c).
Developmentally, young people living with HIV may differ from their peers. Many children and adolescents living with HIV struggle in school or work due to factors such as cognitive delays, behavioral problems and prolonged absences due to illness (Thorne et al., 2002; Zeichner & Read, 2006). As children reach adolescence and become more independent from their families and responsible for their own self-care, clinicians are encountering challenges surrounding medication adherence in HIV-infected adolescents. This is especially concerning due to the high levels of medication adherence necessary for effective achievement and maintenance of viral suppression and to prevent resistant virus strains from developing (NIH, 2008). Biologically, research suggests that puberty and sexual maturation is often delayed in children and adolescents with perinatal HIV infection and growth stunting may occur (DeMartino et al., 2001).

Despite unique HIV-specific challenges, young people living with perinatally-acquired HIV, like other young people, are developing their identities, shifting their focus from parents to peers, and beginning sexual and romantic relationships. Adolescents with perinatal HIV infection are becoming sexually active and engaging in both sexual and drug-use related risk behaviors (Battles & Weiner, 2002; Ezeanolue et al., 2006; Fernet et al., 2007; Weiner et al., 2007a). Several studies are beginning to document issues of reproductive health, including increasingly common reports of pregnancies in HIV-positive adolescents (Brogly et al., 2007; Levine et al., 2005). Since 2005, there have been four reported perinatal exposures to HIV under the category of “mother-to-child” in Canada, meaning that these are infants whose mothers contracted HIV perinatally from their own mothers (PHAC, 2008).
Psychosocial Features

Since HIV may be passed between spouses and to children, it has a multigenerational quality and is often categorized as a ‘family infection’. In addition to all the challenges of growing up with a potentially life-threatening disease, perinatally HIV-infected young people are affected by these multigenerational impacts of the disease such as parental illness and death, grief and mourning. Studies of young people with perinatal infection show that many of them are living in alternative family situations and have experienced the loss of one or both biological parents (Frederick et al., 2000; Grubman et al., 1995; Thorne et al., 2002). A relatively large number of HIV-infected children live in foster care or with adoptive families and some live on their own (Brogly et al., 2007; Grubman et al., 1995). Most attend regular mainstream schools (Grubman et al., 1995; Fernet et al., 2007; Fielden et al., 2006; Frederick et al., 2000; Thorne et al., 2002) but behavioral, adjustment, and cognitive problems are commonly reported in this population (Rao et al., 2007; Gosling et al., 2004). Studies have also reported a high prevalence of depression and anxiety disorders in HIV-positive young people (Battles & Weiner, 2002; Gaughan et al., 2004).

Adolescents with HIV are embedded within the larger context of their families. In acknowledgement of the interconnectedness of family members’ needs, a model of family-centered care for HIV-infected families has been utilized by many organizations and service providers in clinical and community settings (Barrett & Barrett, 1994; DeMatteo et al., 2002b; Spirig, 2002), including those in BC (Kent, 1996). Families deal with many physiological and psychological stresses related to their HIV infection, which can affect family functioning. In a multi-site study involving interviews with HIV-infected parents of both infected and uninfected children representing 91 Canadian families, family illness, death
of parents, orphaned children, parental addictions, poverty, isolation, lack of emotional support, stigma and family secrecy, were just some of the issues HIV-affected families were facing (DeMatteo, 2002b; Antle et al., 2001). Studies in other resource-rich countries support these findings (Lewis et al., 1994; Battles & Weiner, 2002; Barrett & Barrett, 1994; Melvin & Sherr, 1995; Weiner et al., 2000).

Disclosure is one of the most challenging and written about psychosocial issues faced by HIV-infected children and their families (DeMatteo et al., 2002a; Thorne et al., 2002; Weiner et al., 2007b). Disclosure of HIV status in the context of the HIV-infected family occurs most often from parent/guardian to child and is generally viewed as a process rather than a discrete event, affected by parenting philosophies and styles as well as cultural norms (DeMatteo et al., 2002a; Lesch et al., 2007; Salter-Goldie et al., 2007). There are many different strategies of disclosure, with some guardians choosing to disclose to their HIV-infected child at a young age while others struggle to tell even as their children become adolescents (Salter-Goldie et al., 2007). Once children are aware of their HIV-positive status, they must then negotiate disclosure issues with peers and their sexual/relationship partners. Public disclosure has also been examined among those young people and families who chose to be ‘out’ as educators/advocates in their communities, resulting in mixed findings regarding the psychosocial health of the children involved (Weiner et al., 2000). Disclosure to peers, while positively related to social support (Battles & Weiner, 2002), may also lead to rejection associated with the stigmatizing nature of the condition (Weiner et al., 2000).


**Cultural Features**

Although rarely discussed in any profound way in the pediatric HIV literature, young people with perinatally-acquired HIV are also embedded within the cultural norms and traditions of very diverse groups. Studies of long-term survivors of perinatal HIV infection in resource-rich countries like the United States and Canada report largely heterogeneous populations although with disproportionate representation from marginalized ethnic groups. In the United States, Hispanics and African Americans are over-represented among these populations (Frederick *et al.*, 2000; Gaughan *et al.*, 2004). In Canada, the majority of perinatal HIV-infections occur in ethnic groups reported as “Black” in the surveillance data (e.g., Somali, Haitian, and Jamaican) (PHAC, 2008). In British Columbia, Aboriginal children are over-represented, making up approximately 40% of the perinatally HIV infected population (Alimenti *et al.*, 2003; Fielden *et al.*, 2006) despite making up less than 5% of the total provincial population (BC Stats, 2001).

Canadian adolescents living with HIV and their families will also be affected by other social issues (aside from race or ethnicity) that engender health inequities such as poverty, stigma, lack of access to resources, and discriminatory laws and policies (e.g., immigration barriers) (DeMatteo *et al.*, 2002b). HIV stigma will affect families and those other close associates of children and young people living with HIV through increasing isolation and psychosocial stress (DeMatteo *et al.*, 2002b; Faithfull, 1997; Sandelowski *et al.*, 2004). Faithfull (1997) describes the phenomenon of “disenfranchised grief” experienced with HIV-related deaths in the family due to members’ inability to openly discuss the significance of these losses in their lives as a result of HIV stigma.
Overlap with Other ‘At-risk’ Populations

Children with Chronic Illness

Pediatric HIV has been referred to as “the newest chronic illness of childhood” (Meyers & Weitzman, 1991). As with other chronic illnesses, improvements in medical treatment have enhanced quality of life and lengthened the lifespan well beyond original expectations. Long-term survival in childhood chronic diseases is resulting in a proliferation of articles regarding transitions into adult care (Peone et al., 2006; McDonagh & Viner, 2006; Reiss et al., 2005) including some specific to pediatric HIV (Miles et al., 2004; Weiner et al., 2007c). Chronic illness in childhood encompasses a large array of diseases and is generally defined by both the need for health and related services and having a diagnosis of a specific, recognized condition (Sawyer & Aroni, 2005; Van der Lee et al., 2007). Common childhood chronic illnesses discussed in the literature include childhood cancers, diabetes, asthma, and cystic fibrosis. Young people with chronic illness will have many of the same developmental issues faced by healthy children although their development is often complicated by repeated hospitalization, poor health status, or physical and cognitive changes (Taylor et al., 2008). Moreover, and perhaps not surprisingly, they are reported to be just as likely if not more likely than their healthy peers to undertake risk behaviors (Sawyer et al., 2007). Central aspects of managing chronic illness in adolescence are negotiating relationships with peers, family members and professionals, acceptance of illness, emotional responses and meaning-making with regard to living with a disease (Sawyer & Aroni, 2005; Taylor et al., 2008).

HIV shares several common characteristics with other chronic childhood illnesses including: the need for ongoing medical care; pain and discomfort; the psychological impact
on child and family; financial burden; and disruption in daily living (Lewis et al., 1994). One unique aspect of HIV not seen in many other chronic illnesses is its multigenerational characteristic which often involves multiple losses. Thus, it may be quite similar to the genetic diseases in childhood such as Huntington’s and cystic fibrosis. Also, although children with other chronic illnesses (e.g., cancer patients) have been reported to experience stigma associated with their conditions, stigma with HIV is much more acute, and combines elements of public fear of infection and an association with undesirable behaviours or social groups (Gonzalez-Rivera & Bauermeister, 2007; Herek, 1999). Perhaps the most similar population to the young people with perinatally-acquired HIV is the HIV-infected hemophiliac child who lives with two chronic illnesses, hemophilia and HIV. Research addressing HIV infection with hemophiliac children arises primarily out of the Hemophilia Behavioural Intervention Evaluative Project (HBIEP) that followed a cohort of young men from 10 hemophilia treatment centres in the United States. As these children were all infected prior to HIV screening of blood products, implemented in the mid-1980s, these studies provided early examples of the challenges of aging into adolescence with pediatric HIV and challenges related to sexual and substance use risk behaviours (Brown et al., 1995; 2000; Butler at al., 2003; King et al., 1996; Schultz et al., 2001).

As Young People Living with a Disease of ‘Risky Behaviour’

Perinatally-acquired infections make up only a small proportion of the HIV-infected youth population as most young people contract HIV either sexually, or through injection drug use (PHAC, 2007; UNAIDS, 2008). Although studies involving general populations of HIV-infected youth rarely include significant numbers of those with perinatal infection, as children born with HIV mature, they are being integrated with other HIV-positive youth in
terms of surveillance and their clinical and social services. Results from studies of HIV-infected young people raise questions about common characteristics that may impact on both HIV-infected youth with perinatal and non-perinatal HIV-infection.

It is estimated that young people aged 15-24 make up approximately half of new HIV infections worldwide (UNAIDS, 2008). Youth infected with HIV are often marginalized and disenfranchised. Their health may be influenced by multiple factors including unstable housing, substance abuse, and mental health issues (Lam et al., 2007; Martinez et al., 2003; Miller et al., 2002; Rotheram-Borus et al., 2001; Roy et al., 2003; Tenner et al., 1998; Woods et al., 2003). Higher levels of depression in this population have been associated with more unprotected sex and lower levels of social support and coping (Lam et al., 2007; Murphy et al., 2000; 2001). Re-infection, unintended pregnancy, and sexually transmitted infections are significant risks in populations of HIV-infected youth (Levin et al., 2001; Rogers et al., 1998; Vermund et al., 2001; Woods et al., 2003). In the US REACH cohort involving over 150 HIV-positive youth, HIV-infected youth were less likely than uninfected youth to complete schooling with more than a quarter dropping out of school (Rogers et al., 1998). In a Toronto-based needs assessment of 38 HIV-infected youth, financial support was ranked highest, closely followed by housing, and food (CATIE, 2003). HIV-positive youth are clearly at high risk of negative health outcomes and need services tailored to their needs. Although many differences exist between the horizontally-infected and perinatally-infected HIV-positive young people, as the pediatric population ages, similar risk behaviours are emerging and many of the needs will overlap.
Health and Social Service Context for Young People with Perinatally-acquired HIV

In the past, HIV community programs for youth in Canada have been concentrated on HIV prevention rather than treatment and care services for those already infected. In a survey of 32 youth organizations across Canada, the Canadian AIDS Society found that very few provided support or social groups for HIV-positive youth (Canadian AIDS Society, 2000). Some recent initiatives in North America have begun to address the needs of HIV-infected young people including on-line education and support (CATIE, 2009), professional training modules for caring for HIV-positive adolescents (Futterman & Stafford, 2007), and some support programs (e.g., YouthCo, 2009). As part of shifts towards neo-liberalism in Canada and conservative cuts to social programming and funding across the country, the future of HIV programming remains uncertain and a number of HIV-related agencies must compete for a relatively small pool of resources.

In Canada, HIV-infected young people in general are being increasingly recognized as a vulnerable population needing tailored services. Youth-specific programs such as Vancouver’s YouthCo AIDS Society (YouthCo, 2009) and Toronto’s Positive Youth Outreach (PYO, 2009) provide HIV prevention programs and support services for HIV-positive youth and may be well-placed to integrate services for young people with perinatally-acquired HIV. However, according to anecdotal service provider reports, despite the increasing availability of HIV community programs geared towards HIV-positive young people, few adolescents and young adults who are perinatally HIV-infected will access these programs due to population differences in lifestyle (e.g., risk behaviours) and family involvement/circumstances. As discussed above, youth with perinatal infection also resemble
those other young people with chronic diseases. However, young HIV-positive people may be unlikely to access social programs geared towards adolescents with chronic disease due to fear of HIV-related stigma, and concerns of confidentiality. Also, as “youth” tends to encompass a range of ages up to 30 years (United Nations, 2009; Government of Canada, 2009), programs do not tend to focus on or attract younger adolescents at important pivotal developmental stages. Conversely, pediatric HIV programs may be insufficient at meeting the more complex needs of adolescents and young adults and may be perceived as ‘babyish’.

Clinically, adolescents with perinatally-acquired HIV in resource rich countries such as Canada and the United States tend to receive multidisciplinary services by HIV-specialized pediatric and adolescent care teams spread across their respective countries (Alimenti et al., 2007; Rogers et al., 1998). They are routinely seen at these specialized sites every 3-4 months or may access them more frequently if there are more acute health problems (NIH, 2008). However, dependent on local policies concerning age limits and legal definitions of ‘adulthood’ (e.g., 18 or 19 years old across Canada), adolescents will age out of these pediatric services and will need to transition to adult services. The family clinic models such as the one used in BC may help to smooth the transition for children to adult care as only the physicians need change (from pediatrician to adult specialists), depending on the structure. The tertiary care clinic in British Columbia, the Oak Tree Clinic, provides specialized multidisciplinary HIV family services province-wide to all known children and adolescents with perinatally-acquired HIV. Through Canada’s universal health care system, these services are available with no service fee for patients. Prescribed antiretroviral medications for both children and adults in the province of BC are centrally distributed free
of charge through the Drug Treatment Program at the BC Centre for Excellence in HIV/AIDS.

**Summary of the Literature**

The literature summarized above points to the complexity of the clinical, developmental, psychosocial, and cultural aspects of living with perinatally-acquired HIV as a young person. As children mature into adolescence and adulthood, they face a range of ‘normal’ developmental issues such as puberty, independence, and new relationships. However, they must also contend with difficult HIV-specific challenges such as the physical manifestations of disease and treatment, medication adherence, disclosure of HIV to friends and sexual/relationship partners, and cultural meanings of illness and disease. Perinatally-acquired HIV-infected adolescents, although possessing similar characteristics, do not yet ‘fit in’ with other adolescents with chronic illness or ‘HIV-infected youth’ populations that tend to be older and have different life experience. As a result, programs designed for these groups may currently be ill-suited for the perinatal population who will require programs specifically tailored to their needs, either stand-alone or integrated within existing services. As with most adolescent and youth-based research, literature in the area of perinatal HIV infection and adolescence tends to focus on deficits, risk factors, and the problematizing of young people rather than looking at assets and creative solution-based strategies.

**Gaps in Existing Research**

HIV research and programming in Canada and abroad has tended to focus on high prevalence adult populations and de-emphasized children and young people. Recently there
has been a greater acknowledgement that young people constitute a substantial and growing population of people living with HIV. Despite this shift, young people with perinatally-acquired HIV are few in numbers and therefore relatively absent in this movement. The research that does exist regarding pediatric HIV infection has been clinical and epidemiological in nature and has tended to focus on infants or school-aged children. Furthermore, despite the popularity of community-based and participatory research in the larger HIV community, there is a dearth of research in Canada or elsewhere that works with families and their communities to solve problems surrounding perinatal HIV infection or that includes young people themselves in the process. Therefore there is a pressing a need for further exploration of issues relevant to the holistic life experiences of this new cohort of adolescents and young adults living with perinatally-acquired HIV.

**Purpose Statement**

My overall research interests related to combining program development with collaborative processes of inquiry and action to address the needs of young people with perinatally-acquired HIV in BC. This was accomplished through applying the principles of CBPR, working with multiple and varied community actors, and engaging in iterative processes of knowledge production that built on each emerging stage of the project. Through the evolution of the research and its various stages, I sought to answer the following questions:

1. What are the needs of older children and adolescents with perinatally-acquired HIV in British Columbia?
2. What are the processes and challenges of forming an academic-community partnership to address the needs of adolescents with perinatally-acquired HIV in British Columbia?
3. What is the available evidence regarding programming for HIV-infected young people that can be applied to program planning for adolescents living with HIV?
4. What are the core elements of successful program development for adolescents living with HIV?
5. How do interventionists\(^1\)/service providers manage HIV-stigma in their programs for adolescents living with HIV?

**Theoretical Perspective**

This research has been informed and enriched by using an interdisciplinary lens drawing on resources and theories from public health, sociology, social work, and education. However, this work rests primarily on a philosophical and methodological foundation of health promotion, community-based participatory research, and constructivist qualitative inquiry.

Health promotion is defined by the Ottawa Charter of Health Promotion (WHO, 1986, p. 1) as “the process of enabling people to increase control over, and to improve, their health”. It borrows from diverse knowledge and theory ranging from the biomedical to social sciences, thereby making room for both ‘hard’ and ‘soft’ scientific evidence (Potvin & McQueen, 2009). Health promotion theories work at many levels including the individual,

\(^1\) Interventionists in this dissertation include professionals (e.g., health professionals, health educators, and academic researchers) who provide health services through clinical and community programs/interventions.
family, and community to inform research and program development. In practice, health promotion programs work to prevent and manage a wide range of diseases and conditions such as chronic illnesses, infectious diseases, and injuries (Green & Kreuter, 2005). This is accomplished through programs and policies targeting risk behaviours with educational and skills-building approaches that work to empower and/or build capacity with individuals and communities. At the community and structural level, health promotion works to create health-promoting environments and healthy public policy using strategies such as taxation and system changes (Green & Kreuter, 2005; WHO, 1986). Health promotion uses techniques such as community engagement, multiple stakeholder partnership, needs assessment and evaluation and, as it is not married to one specific paradigm or methodology, health promotion is versatile and complements collaborative and community-based approaches to research and program planning.

Community-based participatory research (CBPR) converges with other emancipatory research strategies such as “action research” (Reason & Bradbury, 2001), “participatory research” (Hall, 1992), and “participatory action research” (Fals Borda, 2001). The term “community-based participatory research” is increasingly being used in the field of public health (Israel et al, 1998; Lantz et al., 2005) and is a partnership approach to research “intended to bring together researchers and communities to establish trust, share power, foster co-learning, enhance strengths and resources, build capacity, and examine and address community-identified needs and health problems” (Israel et al., 2005, p. 10). It involves relinquishing power as ‘the researcher’, engaging in a collaborative process of knowledge production, and giving voice to people’s lived experiences (Israel et al., 2005; Wallerstein et
al., 2005). Some say that the role of the academic within CBPR is to shift discourse so that the connections between power and knowledge are weakened and local knowledge may gain currency and space for its expression (Wallerstein et al., 2005).

Constructivist inquiry arose when conventional evaluation was deemed inadequate for addressing and creating meaningful program change (Lincoln, 2001). Constructivism is epistemologically and ontologically based on the idea that realities are co-constructed, subjective, and built through negotiations and dialogue (Guba & Lincoln, 2005). Countering modernist assumptions of an ‘objective’ reality, constructivists tend towards the ‘antifoundational’ whereby there is no fixed or universal ‘truth’. Guba and Lincoln (2005) argue that ‘truth’ and any agreement about valid knowledge “arises from the relationship between members of some stakeholding community” (p. 204). Lincoln (2001) draws parallels between participatory and constructivist forms of research as both focus on tangible realities and socially-constructed realities, designing interventions, redistributing power and taking action on inquiry findings.

The chapters in this dissertation draw on these three research orientations to inform the approaches used to produce knowledge during the multiple stages of the research. These orientations served as a guide for understanding and interpreting the research results, arising from my interactions (as ‘the researcher’) with various types of ‘evidence’, including the literature and perspectives of multiple partners and participants. It is my hope that this work resonates with its readers, presenting useful tools for those wishing to develop, reform or
reflect on health promoting concepts in programs for young people who live on the margins of mainstream culture with HIV or other health conditions.

**Representational Challenges of “The Researcher”**

Reflexivity in qualitative health research has been defined as “thoughtful, conscious, self-awareness” (Finlay, 2002, p. 532) and a way of ‘writing yourself’ into the research. It focuses on the presence of the researcher in the research. “The researcher” here is myself, a white, HIV-uninfected, educated woman with an upper-middle class background. This posed many representational challenges throughout the research project as I negotiated my role in relation to the various ‘others’ who participated and who influenced its course. As a qualitative and community-based researcher I see it as part of my role to create a new identity for “the researcher”, to move away from colonial forms of research and researchers, and towards more equitable forms of generating and benefiting from knowledge. However, I recognize that it is not simply a matter of giving the ‘voiceless a voice’ and that well-intentioned researchers may contribute to the oppression of vulnerable populations through assumptions and actions that reinforce social and cultural hierarchies. In fact, through choosing what I perceive to be less exploitative research methodologies, I may be less prepared to recognize where power differentials exist and how they may create new paths towards inequity in my work.

The very act of writing my research findings into the manuscripts compiled in this dissertation creates a representational crisis as I recognize that it is my interpretation, classification, prioritization, and acts of reconstruction that are represented herein. This dissertation represents my experiences and by no means can recreate all that occurred in the
processes of the research. It is guided and informed by my worldview, experiences, and assumptions.

In this dissertation, I am speaking about the ‘other’, a population of diverse young people dealing with a life threatening illness and psychosocial challenges that are quite unrelated to my own lived experience. While I am in many ways speaking about the ‘other’ from a position of power as ‘the researcher’, I am also speaking as a member of similar social groups or ‘communities’. When I began this research for example I was, by many standards ‘a youth’ or young person, which brought me closer in age to the young population being targeted by the research than to most of the other partners/stakeholders in the research. Conversely, I also had a health professional background in dietetics which is similar to much of the training received by many professionals who participated in the research. The Canadian HIV field is dominated by HIV specialists who are most often senior male researchers and clinicians. It is highly specialized, competitive and fairly profitable for some individuals and groups (e.g., through infusions of research and pharmaceutical dollars). In my work to develop partnerships with practitioners and other researchers in order to gather my data within communities, I was often presented with challenges which may not have arisen if I had a different demographic and professional profile. As a young woman, a non-clinician, a student and novice researcher attempting to conduct research in this environment, I often felt that I lacked knowledge, power, and ‘membership privileges’.

I encountered difficulties associated with combining community-based participatory research and constructivist qualitative inquiry. This arose from my desire to build a process
that was driven by participants and to produce tangible benefits for them while maintaining the position that there is no one “true” answer to a problem and that the research outcomes were not predetermined. I believe that this is especially problematic in health research where quantitative disciplines such as epidemiology prevail and are privileged by potential research partners and stakeholders. By giving away what little power I might have been able to garner had I positioned myself as an “objective” scientist, I may have placed myself at a disadvantage for building and maintaining trusting relationships with and delivering ‘results’ to partners who aligned with more traditional positivist research approaches.

According to Finlay (2002), with reflexive analysis, the researcher is present and moves back and forth between experience and awareness. The representational challenges I describe crystallized as I guided and experienced the research processes of defining questions, executing methods, and disseminating findings. As I reflected on my role in the research and worked to define myself as ‘insider’ and ‘outsider’ in relation to the various communities and participants, I became aware of how my background, personality, and other personal characteristics shaped the direction and deliverables of my work.

Chapter Summaries

This dissertation has seven chapters. In order to disseminate the research widely and quickly within the academic and practitioner communities, and to maximize the utility of the results, this dissertation format is manuscript-based with each of the chapters representing a distinct manuscript for publication. The exceptions to this are this, the introductory chapter (Chapter 1), and the final concluding chapter (Chapter 7).
The first manuscript chapter (Chapter 2) entitled “Growing up: the needs of older children with pediatric HIV in BC” examines the needs of a cohort of older children with perinatally-acquired HIV in the Canadian province of British Columbia. The community-based qualitative needs assessment used focus groups and semi-structured interviewing techniques with the HIV-positive children and adolescents, their caregivers/guardians, and their healthcare and social service providers. This study used collaborative approaches to identify and prioritize the needs of the young people, pooling the data from the various stakeholders to identify needs and highlight gaps in current service provision. Priority areas of social stigma, sexual health, and mental health are outlined. The voices of the child participants dominate this chapter as the basis for developing new areas of program development, calling for more psychosocial support and education to help resolve the unmet needs of this population of young people.

Chapter 3, “A Canadian case study of collaborative research partnerships: Planning community-based programs for HIV-infected adolescents.” This chapter outlines the various stages of program planning undertaken to create a theoretically and empirically driven health promotion model. In a climate of increased accountability to funding agencies and government, well designed and articulated planning and evaluation processes are paramount to program success and sustainability. As part of the current public health paradigm, concurrently emphasizing evidence-informed programs and collaborative research partnerships, this paper describes a case of program planning for a particular group of perinatally-infected HIV-positive adolescents. This progresses from identifying and defining “the community” and their needs to consulting with various local, national, and international
sources; and then returns to the local context where new partnerships congeal to apply the knowledge gained. This chapter touches on critical technical, socio-political and ethical issues arising during the partnership process, both as facilitators and barriers to research and program implementation. In essence, Chapter 3 serves as an overview chapter, touching on all parts of the project and bringing the thesis segments together as a cohesive whole. It includes brief descriptions of the research described in chapters 2, 4, 5, and 6 and relates them to the processes that unfolded during the course of the project. It follows the needs assessment chapter because the solidification of the partnership was a direct result of identifying program gaps and needs in the initial phases. It outlines the stages and results of program development undertaken to meet the needs of adolescents living with perinatally-acquired HIV in BC, forming the basis of the final chapters.

In order to create a program informed by the best available evidence, it was useful to examine existing literature regarding intervention models and best practices. Chapter 4, “A review of intervention and programming articles targeting young people living with HIV: How can evidence inform “prevention for positives” youth programs?”, examines this literature through a critical review process, including a narrative review of peer-reviewed articles describing programs for HIV-infected adolescents. The original purpose of this review was to locate population-based evidence to guide program development for the BC population of adolescents with perinatally-acquired HIV. In light of extremely limited evidence on effective programming strategies for this population, the review includes reports about programs for HIV-positive youth generally as well as programs that provide services for ‘HIV-positive and high-risk youth’ in order to identify a wider body of evidence. It
explores the difficulties of synthesizing the ‘evidence’ and provides recommendations for future studies and syntheses in order to better inform researchers, programmers, and policy-maker developing programs for populations of HIV-positive young people.

Building on the reviews and given the dearth of literature specific to programming with adolescents post HIV-infection, Chapter 5 “Core elements for successful programming with HIV-infected adolescents in resource-rich countries: expert perspectives” uses another approach to gain knowledge and insight through integrating the perspectives of ‘the experts’ in adolescent HIV care\(^2\). This section presents the findings from a qualitative study of 15 international experts (US, Canada, Australia, and the UK), including interventionists and service providers. The objective of this study was to identify and prioritize the core elements of successful programs for adolescents living with HIV. Through in-depth interviews, experts reflected on overarching essential elements of program development and implementation when working with this population. The study findings suggest 10 primary domains that were expanded, integrated, and interpreted to create a question-based tool for program planning and evaluation (ADOLESCENCE) with HIV-positive adolescents.

The final manuscript chapter “Managing stigma with HIV-positive adolescents: silences, secrets, and sanctioned spaces” explores the responses of the interventionists (‘the experts’) in relation to promoting the health of HIV-positive adolescents living with a highly stigmatized condition. It draws on social theory and various disciplinary perspectives to

\(^2\) Although “expert” is a contentious term and I acknowledge differing forms of knowing and expertise including lay and local forms of knowledge throughout this dissertation, ‘the experts’ referred to here and in later chapters are defined as those with professional titles, training, and more “dominant” forms of knowledge (Gaventa & Cornwall, 2001) such as service providers and academics.
explore and explain strategies applied in stigma management. It looks at how different agents and environments construct and reconstruct internal, relational, and physical spaces of silence. It explores power in relation to ‘the minor’ and how silence is used intentionally and unintentionally, individually and structurally, and in different spheres of adolescents’ daily lives. The synergistic impacts on adolescents, family members, and experts are outlined for future consideration in health promotion programming.

This dissertation concludes with a discussion of implications for service development and delivery. I draw on the various stages of the research and the co-learning that occurred in the different settings and with the stakeholders to illustrate and summarize the practical application of this research. In this final chapter, recommendations and future direction for research, programming and policy are outlined.
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Rates of mother-to-child HIV transmission have decreased dramatically in developed countries over the past decade (European Collaborative Study, 2001; Madger et al., 2005) with the advent of combination antiretroviral therapy and improved perinatal management. Children born with HIV are now living longer and healthier lives (Foster & Lyall, 2005; Gibb et al., 2003).

The needs of these children are influenced by a myriad of strengths, challenges, and stresses. To date, few studies have examined the issues affecting long-term survivors of perinatally-acquired HIV and they have relied heavily on clinical data and chart reviews (Papola et al., 1994; Salvini et al., 2001; Thorne et al., 2002). While these methods are valuable, they do not include direct consultation with professionals, families, or the children themselves whose voices are crucial in assessing needs and determining which services are appropriate. In this community-based participatory study (Green et al., 1995), all of these people were recognized as integral to the care of HIV-infected children and youth. Their voices are crucial in determining which services are appropriate for targeting the needs of HIV-infected children and youth. This study sought to examine the needs of older children with perinatally-acquired HIV in BC from the perspective of service providers, family members, and the children and youth themselves.

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3 A version of this chapter has been published. Fielden, S. J., Sheckter, L., Chapman, G. E., Alimenti, A., Forbes, J. C., Sheps, S., Cadell, S., & Frankish, J. C. (2006). Growing up: Perspectives of children, families, and service providers regarding the needs of older children with perinatally-acquired HIV. *AIDS Care, 18*(8), 1050-1053.
Methods

Participants were recruited through a tertiary care multidisciplinary clinic providing specialized medical care to all the children and youth known to be HIV-infected perinatally in British Columbia (BC), Canada. All children, youth, and family members who met the selection criteria were selected by clinic staff and asked to participate. Service providers were purposefully sampled to represent a range of disciplinary perspectives including social work, pharmacy, pediatric medicine, child psychiatry, dietetics, and family and child HIV community services. The distinct participant groups were chosen to encourage open dialogue between peers during the focus groups and to get a cross-section of perspectives from people with different types of influence in the children and youth’s lives; including the children and youth’s perspectives. Ethical approval was granted by the Behavioural Research Ethics Board at the University of British Columbia and the Research Review Committee at the Children’s and Women’s Health Centre of British Columbia (see Appendix A).

Data were collected through four focus groups and seven in-depth interviews, using semi-structured interview scripts consisting of open-ended questions reflecting the objectives of the study. Data collection was conducted over a period of five months (October 2003 to February 2004). Field notes were taken during the focus groups and interviews and a reflective journal was kept by the primary researcher (first author). Focus groups were chosen as the primary method for this study because of their strength as an empowering approach with vulnerable groups (Horner, 2000) and to ensure nearby professional psychosocial support. The focus groups were conducted using a workshop format with a series of questions designed to identify needs and develop some suggestions and strategies
for action. The interviews were a second cycle in the research and followed a similar format. Interview participants were selected specifically when they were unable to attend focus groups and when it was believed they would provide additional insight and elaborate on certain issues which emerged from the focus groups. Each focus group and interview addressed similar questions based on the objectives of the study in order to be able to pool the results for analysis. Collage was used during the children’s group to allow creative expression of their ideas and as a vehicle for discussion. Focus groups were sequenced intentionally to build on ideas of the children and youth with their focus group held first, followed by the familial caregiver group, foster parent group, and service provider group. Focus groups were conducted in a clinical setting by the same two-person team, the first and second authors, acting as facilitators and researchers. Interviews were conducted in participants’ homes by the primary researcher. Debriefing sessions were held after each focus group with the researchers and one or two participants comparing and reviewing the key elements of the discussion, discussing the process, and identifying noteworthy points for future consideration.

Analysis was guided by the principles of qualitative inquiry (Pope & Mays 1999) and was a multi-step process. This was initially begun collaboratively in each focus group with participants identifying major issues and then categorizing them under thematic areas. Responses from all the focus groups were later pooled together by the primary researcher to create a broader thematic framework. Guided by the work of Morgan & Krueger (1998), each of the focus groups and debriefing sessions was audio-recorded, transcribed, coded, and indexed to verify themes and to identify sub-categories within themes as well as descriptions
of participants’ experiences. Interview transcripts underwent similar analysis using NVivo qualitative software (QSR International 1999).

Several participatory strategies were employed to encourage the involvement of participants in the design, implementation, and dissemination of the research. A community advisory committee consisting of potential participants was established and provided direction for conducting the research (e.g., reviewing the focus group scripts). A focus group facilitation training session was conducted with several of the adult\textsuperscript{4} committee members (including parents and service providers) who then assisted with conducting the groups and categorizing the data. All participants in the study were invited to take part in the data analysis and dissemination of the findings and to contact the researchers with any additional feedback or questions. In March of 2004, two of the study participants (included one minor) joined the researchers to participate in a national conference on children, youth, and families affected by HIV. Review of the research design, scripts, and findings by practitioners and research participants as well as peer-debriefing with university researchers contributed to the rigour and trustworthiness of the research findings.

**Results**

**Sample Characteristics**

Thirty-two stakeholders participated in either focus groups or individual interviews. The group composition and methods are outlined in Table 2.2. Table 2.3 outlines select characteristics of the study sample compared to the population of perinatally-infected HIV-

\textsuperscript{4} The HIV-positive young person on the Committee was invited but unable to attend the facilitation training session.
positive children and youth, and illustrates the diversity existing within both groups. The HIV-infected children and youth in this group came from varied family situations and many were members of culturally marginalized groups, with a disproportionate number of Aboriginal children and youth and people living on social assistance. Several children and youth had significant behavioural problems, attention deficits, or school difficulties and approximately half had been exposed to illicit drugs and alcohol in utero. Most of the children, youth, and family members who chose not to participate tended to live further away from Vancouver and/or indicated they were either not ready or not willing to talk about HIV.

**Perspectives of Children and Youth Participants**

The children and youth all seemed to enjoy the focus group experience and each other’s company. It was clear, however, that many children and youth in the group were not ready to discuss their HIV in a group setting. Despite this, it could be inferred from the children and youth’s collages and comments that many were showing an interest/curiosity about sexual matters, and that they were largely interested in recreational activities. After the session, some of the youth expressed their desire to learn more about HIV and expressed concerns about their health and future to the focus group facilitators. During the focus group, most of the children and youth enjoyed doing the collages addressing the question “What is good and what is bad in your life?” When children and youth talked about their pictures and their lives, they talked mostly about what they liked to do with friends and family in terms of recreational interests such as skateboarding, music, biking, pets, travel and games. This group of children and youth did not include any mention of HIV or anything considered “bad” as part of their collages. Also, despite the provision of magazines targeted at Aboriginal youth and the large proportion of Aboriginal children, none of the children and
youth chose pictures from these resources to include in their collages. When asked what would make their lives better, some of the children and youth talked about wanting a cure for HIV and wanting immortality. The children and youth had unique responses about who could help make their lives better, including God, their parent(s) or caregiver, and themselves. They also had many ideas about recreational activities they could do together as a group such as rock-climbing, bowling, and movie nights. Whereas the ages of those children who participated in the focus group tended to be younger, the children interviewed were already teenagers and seemed better able to think abstractly and reflect on the reality of their HIV-infection. They were able to articulate their concerns regarding issues such as stigma, disclosure, medications, and sexual education.

Major Issues Affecting Older HIV-infected Children and Youth

While children and youth rarely made reference to HIV and focused on recreational program suggestions, adult participants in the study voiced concerns and strategies for support and education. Familial caregivers and foster parents spoke candidly about their social experiences, concerns about discrimination, and fears about their child transmitting HIV to others. Service providers had concerns about gaps in service provision as the group matured. Participants from all stakeholder groups emphasized the children and youth’s shared and inter-related needs in the areas of social stigma, mental health, and sexual health. This paper highlights the perspectives of the participants concerning these three areas of need.
Social Stigma

Social stigma was emphasized as a negative and destructive influence on the well-being of the HIV-infected children, youth, and families. It was associated with concepts of fear, secrecy, trust, disclosure, and isolation. Some families have disclosed to school personnel, friends, and extended family members whom they trusted to keep the secret but, as one foster parent stated: “it’s hard to come to a place where you trust.” One young person in the study explained her apprehension about telling other people:

*A lot of people know who I am but I don’t really want to be like one of those people who are the centre of attention, and everybody is like, 'Oh, lookit! There’s the girl with HIV' and 'I’d rather people see me as Lucy, than people see: oh, Lucy with HIV."

Another young person spoke of the way her friends joke about HIV: “some of my friends or some people were like, they are drinking pop and they’re like ‘oh no. you might get AIDS from that…’ I’m like looking at them like ‘oh my God, you have no idea!’” It is evident however that some of the children and youth want to be able to tell people in their lives that they have HIV. During interviews with two of the oldest participating youth, both said that having to keep their HIV status from their friends was a bad part of their lives.

Whether or not disclosure occurs seems to depend on the context and the people involved. For example, some children and youth seemed to be more willing to disclose to

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5 All names are pseudonyms.
friends at the summer camp for HIV-infected and HIV-affected children than to their school friends, illustrated in this young person’s comment:

*It’s nice to go to camp because like I don’t tell any of my friends here that I have HIV.*

_They don’t know anything of that, right. I’m just a regular kid, right… Then, when we go to camp everybody has this in common, so it’s like you can just kind of feel really relaxed and just, you know, whatever, be really, really happy, know that everything’s okay and everybody like knows and everybody’s going to support you and not sit there and feel sorry for you or change their opinion of you…_

However, when it came to people closer to home, in their own communities and schools, families, children, and youth were reluctant to disclose the child’s status because they either anticipated and/or had experienced negative consequences such as losing friends. Many participants discussed the problems associated with disclosing to others. During an interview, one healthcare provider stated: “I think the secret is to some extent absolutely necessary to allow them that privacy to be able to function in school and other activities.” Providers reported having “incidents” over the years in communities that have required professional communication and teaching to resolve. Only a few parents or children/youth have disclosed to school personnel because of the anticipated negative reaction of the staff, the other children/youth, and the other children/youth’s parents. The size and diversity of cultural communities also seemed to have an impact on families’ comfort disclosing their status.
Mental Health

With the many complex medical and psychosocial issues that have an impact on the children and youth, mental health needs and concerns were notable. Mental health can be impacted by a number of HIV-related and HIV-unrelated issues such as opportunistic infections, fetal alcohol syndrome, and poor socioeconomic status. Collectively, participants raised issues concerning children and youth’s emotions, bereavement, feeling “normal”, security, stability, self-esteem, and having a positive attitude. Despite various supports, the children and youth have worries and anxieties that most other children and youth their age do not have such as having their parents die before they can adequately take care of themselves or being rejected by a girlfriend or boyfriend when they disclose their HIV status. Most of the children/youth have been orphaned. Parents and care providers stressed the need for the children/youth to feel “normal” despite their HIV.

Maintaining a positive attitude seems to play a role in the ability of families, children, and youth to live a “normal” life. Despite the perceived need for mental health services, some of the children and youth were very clear that they would not like to participate in support groups that involved talking about their disease and problems. Two of the children/youth shared their thoughts about this: “because if you think about it a lot then you’re always going to be like down and stuff like that; always looking for some comfort and stuff and I don’t want to do that” and “If you are positive, you’re probably a little more healthier than being “oh, I’m going to get sick and this is never going to go away or anything.”
Sexual Health

Many of these children and youth are starting to be curious about sexual relationships. Unlike other children and youth, their sexual health is complicated by their HIV from the very beginning of their sexual development. Some of the older children/youth already had had sexual experiences and/or romantic relationships. Although they are educated by healthcare providers and parents to disclose their status to their sexual partners, some are concerned about maintaining a relationship when they disclose to a boyfriend or girlfriend. One participant explained her approach to relationships:

...in the future, if I’m still going out with this person and we eventually want to have sex, I’m going to have to tell him this [her HIV status], ‘cause you know, I just think that he should know before having sex with me. It’s just like that. Like having kids, you know? I really want to have kids and that’s going to be; I guess it could be an issue. I guess maybe it couldn’t. I don’t know though.

Sexual health issues raised by adult participants tended to focus on sexual education, and concerns about partner disclosure. During the discussions, some familial caregivers expressed a need for education and support around providing guidance to their children about sexual health. Sexual health raised many questions for some caregivers such as those of one parent: “Like what do you say to them? I mean are you allowed to go on a date? Are you allowed to make out with somebody? What do you do? Do you reveal your whole medical issue to the person?” Some of them also expressed their apprehension with dealing with the issue of sexuality with their children as demonstrated by this comment: “I think it’s tough enough to deal with the sex thing as it is or the puberty thing as it is, let alone to have to deal
with the HIV and the puberty.” Service providers spoke of the need for tools to deal with the children and youth’s sexual development in the future.

Currently, the children and youth are receiving HIV-related sexual health information from the healthcare providers and within their families. They also receive information about sex and HIV from their peers, at school, and in the media; much of which is negative or stigmatizing. One healthcare provider emphasized the need for young people to have positive sexuality:

*I think (it’s important to) give them a positive approach to their sexuality... It can get tainted so easily because these kids are so in touch with community resources... and a lot of them know about HIV... seeing posters saying HIV, safe sex, all that stigma, all that anti-sexuality... (they) need to feel positive about their bodies and sex.*

These issues of sexuality, partner disclosure, and family planning are going to be increasing concerns as more of the children enter adolescence and approach adulthood.

**Discussion**

The findings from this study offer insight into the experiences of children and youth living with perinatally-acquired HIV. HIV intersects with societal and psychosocial issues, impacting on the lives and well-being of this unique population of young people in BC. The service providers, family members, and children and youth described and highlighted the importance of social stigma, sexual health, and mental health in the children/youth’s lives and the need to address these in future programming.
Bell and colleagues (2003) describe HIV-infected adolescents as a “hidden population”, due to “covert” behaviours and sampling difficulties associated with this high-risk population. The children and youth with perinatally-acquired HIV targeted in this study are best characterized as a population ‘in hiding’ due the experience and fears of HIV-associated stigma. Similar to DeMatteo and colleagues’ (2002) study with HIV-affected families, findings from this study showed stigma was a dominant theme. The children and youth in this study experienced stigma through their own and their family’s interactions with their friends, the school system, and their communities. As Goffman’s (1963) seminal work has suggested, stigma, in this study, appeared to be contextual – varying from one situation to another depending on others’ knowledge and experience of HIV. Disclosure issues, originating from both the “felt” (internal) and “enacted” (external) stigma, were predominant in discussions with children, youth, families, and services providers; especially when it came to close friends and intimate partnerships. Participants talked of their fears and apprehensions; being forced to confront prejudice and make difficult decisions about who to trust. In addition to experiencing these fears and concerns, this study also revealed that young HIV-infected participants were negotiating other difficult issues in their lives such as building self esteem, dealing with the death of a loved one, and fitting in with peers. Studies of HIV-infected youth with variable modes of acquisition also alert families and professionals that issues such as depression, bereavement, anxiety, and suicide ideation are potential mental health concerns for HIV-positive youth (Battles & Weiner 2002; Murphy et al. 2000).
This study also highlights the importance of healthy sexual development for HIV-infected children now maturing into adolescence and adulthood. The findings confirm a need for support for children and youth, especially surrounding partner disclosure and family planning. Policies and services that ensure children receive timely and appropriate sexual education are essential. Findings from other studies have highlighted the need for prioritizing sexual health issues for young people with perinatally-acquired HIV as well as the general population of HIV-infected youth. One such study was conducted in Puerto Rico and described the pregnancies and outcomes of eight women with perinatally-acquired HIV (Center for Disease Control 2003), thus illustrating the immediacy of the sexual health issue. In the Pediatric Spectrum Disease Project, at least 27% of adolescents with perinatally-acquired HIV were sexually active (Frederick et al. 2000). One of the adolescents in the BC cohort was already sexually active (Alimenti et al. 2003). Risky sexual behaviours, reinfection, and other sexually transmitted infections are reportedly a problem in other populations of HIV-infected adolescents (Miller et al. 2004; Murphy et al. 2001; Vermund et al. 2001) and will also need to be considered for this population.

As with any qualitative study, the results of this community-based research are not meant to be generalized beyond the group studied. The findings are of value, however, in serving as an educational tool for the children, youth, families, and professionals working in the area of HIV care in the province. As well, the detailed information provided here about the demographic characteristics and context of the study sample will allow readers to assess the degree to which findings can be applied in other contexts (Lincoln and Guba, 1986). We expect that the perceptions and experiences described by the participants resonate for
families and professionals elsewhere. This study is a useful addition to existing HIV research, creating a more holistic and prospective vision of the health of perinatally HIV-infected children and youth. A possible limitation of the research methodology is that when compared to individual interviews, focus groups may not enable the depth of discussion on complex topics or allow for as much flexibility to allow for the needs and abilities of individual children. Focus groups also cannot provide the same assurances about confidentiality and anonymity because other children are privy to the conversations. However, O’Kane (2000) cites several advantages to focus groups including: discovering group norms; highlighting respondents’ attitudes, knowledge, priorities and frames of reference; using the group setting to explore interaction between children; and putting children at ease to discuss sensitive topics. Another strength of this study is the involvement of the young people with HIV and the various adults in their lives in the research process; giving a voice to concerns that have personal relevance for them.

Further research should seek to elucidate the issues of stigma, mental health, and sexual health through in-depth examination of: personal factors such as resilience and self-efficacy; social factors such as support systems and independence from family; community factors such as education and recreation; and political factors such as child welfare policies. All of these can potentially facilitate or inhibit the healthy future development of this population of maturing children. Research such as that of Miles and colleagues (2004), that examined the transition experience of HIV-infected children from pediatric to adult clinical care, illustrates the need for effective healthcare and social service models targeting the
burgeoning needs of these young people. These need to be developed and shared amongst academic, professional, and lay audiences alike.

Adolescence is a time of rapid change characterized by transitions, experimentation, and self-discovery. It is a time when children begin to develop their adult identities, become more independent from their families, and plan for their futures. Children infected with HIV will face not only the typical trials of being teens, but also may face additional difficulties due to their HIV-infected status such as societal discrimination, sexual health with HIV, and issues such as grief and isolation that may be challenging to their psychological and emotional wellness. The future well-being of these young people requires two major developments: interventions tailored to their unique age and stage-specific medical and psychosocial needs; and the empowerment, support, and education of HIV-infected children and youth, their families, and the professionals who care for them.
Table 2.1: Principle Questions in Focus Groups and Semi-structured Interviews

<table>
<thead>
<tr>
<th>Concept</th>
<th>Questions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Transition</td>
<td>• <em>What do you think of when I say “Living Positive”?</em> (All)</td>
</tr>
<tr>
<td>Identifying needs and resources</td>
<td>• <em>Name things that would make your life happier and healthier.</em> (Children)</td>
</tr>
<tr>
<td></td>
<td>• <em>What is good in your life</em> (Children)</td>
</tr>
<tr>
<td></td>
<td>• <em>What is bad in your life</em> (Children)</td>
</tr>
<tr>
<td></td>
<td>• <em>What do your/these children need in their lives to be healthy and happy</em> (Adults)</td>
</tr>
<tr>
<td></td>
<td>• <em>What is going well in your/these children’s lives? Why?</em> (Adults)</td>
</tr>
<tr>
<td></td>
<td>• <em>What would you say are the major needs/ issues/ concerns/ problems that impact on your/ these children?</em> (Adults)</td>
</tr>
<tr>
<td>Identifying Solutions</td>
<td>• <em>Who or what can make your life better?</em> (Children)</td>
</tr>
<tr>
<td></td>
<td>• <em>What can be done to make your/these children’s lives better?</em> (Adults)</td>
</tr>
<tr>
<td></td>
<td>• <em>Which strategies are the most important and realistic</em> (Adults)</td>
</tr>
</tbody>
</table>
Table 2.2: Study methods and group composition

<table>
<thead>
<tr>
<th>Method</th>
<th>Participant Category</th>
<th>Number</th>
<th>Gender M:F</th>
</tr>
</thead>
<tbody>
<tr>
<td>Focus Group #1</td>
<td>Child/Youth</td>
<td>8</td>
<td>5:3</td>
</tr>
<tr>
<td>Focus Group #2</td>
<td>Familial Caregivers</td>
<td>3</td>
<td>2:1</td>
</tr>
<tr>
<td>Focus Group #3</td>
<td>Foster Parents</td>
<td>5</td>
<td>3:2</td>
</tr>
<tr>
<td>Focus Group #4</td>
<td>Service Providers</td>
<td>8</td>
<td>2:6</td>
</tr>
<tr>
<td>Interview #1</td>
<td>Child/Youth</td>
<td>1</td>
<td>0:1</td>
</tr>
<tr>
<td>Interview #2</td>
<td>Familial Caregiver</td>
<td>1</td>
<td>0:1</td>
</tr>
<tr>
<td>Interview #3</td>
<td>Service Provider</td>
<td>1</td>
<td>0:1</td>
</tr>
<tr>
<td>Interview #4</td>
<td>Service Provider</td>
<td>1</td>
<td>0:1</td>
</tr>
<tr>
<td>Interview #5</td>
<td>Service Provider</td>
<td>1</td>
<td>0:1</td>
</tr>
<tr>
<td>Interview #6</td>
<td>Child/Youth</td>
<td>1</td>
<td>0:1</td>
</tr>
<tr>
<td>Interview #7</td>
<td>Familial Caregivers</td>
<td>2</td>
<td>1:1</td>
</tr>
</tbody>
</table>
Table 2.3: Select characteristics of children ≥ 9 years with vertically-acquired HIV in BC: study sample versus population data

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Sample N=10</th>
<th>Population N=18</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N (%)</td>
<td>N (%)</td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>5 (50)</td>
<td>10 (56)</td>
</tr>
<tr>
<td>Female</td>
<td>5 (50)</td>
<td>8 (44)</td>
</tr>
<tr>
<td><strong>Age (years)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9-10</td>
<td>4 (40)</td>
<td>7 (39)</td>
</tr>
<tr>
<td>11-12</td>
<td>3 (30)</td>
<td>6 (33)</td>
</tr>
<tr>
<td>13-16</td>
<td>3 (30)</td>
<td>5 (28)</td>
</tr>
<tr>
<td><strong>Ethnicity</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Caucasian</td>
<td>2 (20)</td>
<td>7 (39)</td>
</tr>
<tr>
<td>Child of colour</td>
<td>3 (30)</td>
<td>4 (22)</td>
</tr>
<tr>
<td>Aboriginal</td>
<td>5 (50)</td>
<td>7 (39)</td>
</tr>
<tr>
<td><strong>Caregiver</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Two biological parents</td>
<td>0 (0)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Foster parent(s)</td>
<td>5 (50)</td>
<td>9 (50)</td>
</tr>
<tr>
<td>One Biological Parent</td>
<td>3 (30)</td>
<td>6 (33)</td>
</tr>
<tr>
<td>Sibling or Grandparents</td>
<td>2 (20)</td>
<td>3 (17)</td>
</tr>
<tr>
<td><strong>Treatment</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>On Antiretroviral Therapy</td>
<td>7 (70)</td>
<td>15 (83)</td>
</tr>
<tr>
<td>Treatment Interruption</td>
<td>3 (30)</td>
<td>3 (17)</td>
</tr>
<tr>
<td><strong>Attends school</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>10 (100)</td>
<td>18 (100)</td>
</tr>
<tr>
<td>No</td>
<td>0 (0)</td>
<td>0 (0)</td>
</tr>
<tr>
<td><strong>School/Behavioural difficulties</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>7 (70)</td>
<td>11 (61)</td>
</tr>
<tr>
<td>No</td>
<td>3 (30)</td>
<td>7 (39)</td>
</tr>
<tr>
<td><strong>Attends summer camp</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>10 (100)</td>
<td>14 (78)</td>
</tr>
<tr>
<td>No</td>
<td>0 (0)</td>
<td>4 (22)</td>
</tr>
</tbody>
</table>
References


Chapter 3: A Canadian Case Study of Collaborative Research Partnerships: Planning Community-based Programs for HIV-infected Adolescents

Introduction

In public health and health promotion, we have seen the popularization of approaches meant to narrow the gap between community programs and ‘ivory tower’ research. These approaches include community-based participatory research, academic-community partnerships, and intervention/program research as well as an emphasis on ‘knowledge translation’ back to communities. The shared focus of these methodologies is the application of research knowledge in real world settings through collaborative processes in order to create more effective clinical, psychosocial, and community programs. Although many would argue that these partnerships and community-based processes are ideal for addressing complex health issues faced by vulnerable populations, developing research partnerships for evidence-informed programming is not without its challenges. The purpose of this paper is to describe the processes involved in a community-academic research partnership meant to inform community program development for a vulnerable population of young people, those living with perinatally-acquired HIV in the province of British Columbia (BC), Canada.

Community-academic partnerships are rising in popularity as a genre of community-based participatory research (CBPR). Researchers have already described many of the challenges and facilitators associated with CBPR (Lantz et al., 2005; Israel et al., 1998). Challenges include lack of trust and respect among prospective partners; inequitable

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6 A version of this chapter will be published. Fielden, S.J. A Canadian case study of collaborative research partnerships: Planning community-based programs for HIV-infected adolescents.
distribution of power and control; conflicts associated with different perspectives, priorities, values, beliefs, and language; limited resources; and difficulties in balancing research and community goals. On the other hand, CBPR potentially creates research that is more salient to communities and interventions that are more likely to be accepted and therefore implemented and tested in the ‘real world’. It can facilitate research relationships that are based on trust, mutual respect, and a shared commitment to positive social change (Israel et al., 1998; Lantz et al., 2005). Working with children and young people, considered members of vulnerable populations (by virtue of their development, legal, and social status), adds another layer of complexity that is rarely discussed in the HIV and public health literature.

“Vulnerable populations” have been defined in the health literature as social groups that have an increased susceptibility or higher than average risk of health-related problems (Flaskerud & Winslow, 1998). Constructs of vulnerability are linked to broader notions of ‘health equity’ and social structures that confer agency and power. Vulnerability can result from financial circumstances, place of residence, health, age, functional or developmental status, and personal characteristics such as race, ethnicity, or sex (Purdy, 2004). Groups typically conceptualized as vulnerable include those living in poverty; persons subjected to stigma, discrimination and subordination; and those that are politically marginalized and denied human rights (Flaskerud & Winslow, 1998).

Children and adolescents born with HIV are among some of the most vulnerable individuals in our society. With the advent of Highly Active Antiretroviral Therapy (HAART) and other medical advances over the past decade, HIV has become a chronic
disease and children born with perinatal HIV infection are now maturing into adolescence and adulthood (Prendergast et al., 2007). Unfortunately, their lives are often characterized by familial difficulties, health concerns, isolation, and secrecy (Frederick et al., 2000; Steele et al., 2007; Cree et al., 2006). Despite great improvements in health outcomes, those born with HIV have a disease that remains incurable, that increases risk of morbidity and mortality (Judd et al., 2007; Prendergast et al., 2007), and that may have other negative physical effects such as growth stunting and delayed sexual maturation, pain, and cognitive impairment (De Martino et al., 2001; Gaughan et al., 2002; Rao et al., 2007). Psychosocial and cultural challenges may include but are not limited to illness or loss of HIV-infected family members, mental health issues such as depression and other psychiatric disorders, poverty, and social stigmatization (Abadio-Barrero, 2006; Battles & Wiener, 2002; Fernet et al., 2007; Mellins et al., 2006). Given the considerable physical, social, and cultural vulnerability of this population of children and adolescents born with HIV, they are key targets for health programs promoting risk prevention, positive youth development⁷, and optimal quality of life. However, working with vulnerable populations such as this will present community health program planners and researchers with unique challenges such as ethical dilemmas surrounding informed consent, avoiding coercion, and difficulties with locating and engaging participants.

Existing health planning models are useful yet insufficient for health promotion planning for vulnerable populations such as children and adolescents living with HIV. Many frameworks/models popularized in public health such as ecological frameworks (e.g.,

⁷ “Positive Youth Development” is a concept that arose in the field of Child Development in the 1990s that moved away from a “deficit model” of viewing young people in favour of the “5 C’s”: competence, confidence, connection, character, and caring. (Lerner et al., 2005)
Precede-Proceed), program evaluation tools (e.g., logic models), and behaviour change models (e.g., Stages of Change), provide useful guides and theoretical lenses for planning (Glanz & Rimer, 1995; McLaughlin & Jordan, 1999). However, models and theories often fall short when it comes to describing or providing the specific skills and resources necessary for program development (e.g., relationships, leadership, and negotiation). Researchers and planners in the field of Education have been highly criticized and self-critical when it comes to applying planning models to real life problems and contexts. As Wilson and Cervero (1996) note: “theories do not plan programs - people do” (p. 5). Existing planning models have been said to provide an overly linear and ‘rosy’ picture of the processes involved in developing successful programs and their evaluation, while under-valuing the impact of more relational, often ‘messy’ business of “people work” (Wilson & Cervero, 1996). This paper will attempt to describe some of this ‘messiness’ by detailing process elements and presenting lessons learned from the “HIV/AIDS Youth and Child Umbrella Program” (HYCUP) Initiative, a Canadian community-academic partnership which aimed to develop a health promotion program model for adolescents living with perinatally-acquired HIV in British Columbia, Canada.

Thomas Sork, an established researcher in planning and adult education, describes three domains of program planning: the technical, the social-political and the ethical (Sork, 2000). In this paper, these domains will be used as a framework for presenting the processes and lessons learned in order to elucidate the complexity of the partnership and program development and provide examples of challenges. The HYCUP case study illustrates how community-based participatory research (CBPR) may be used to provide foundational
evidence for health programs with vulnerable populations. This paper argues in favour of viewing community program development and CBPR as symbiotic processes, benefiting from collaborative, iterative approaches, embracing post-modern ideas of relational, contextual, and co-constructed knowledge.

Planning Processes

Identifying the Approach

The goal of the HYCUP research was to work collaboratively with HIV-infected young people, their families, and their service providers to assess needs and design a theoretically and empirically-informed program model to assist in meeting these needs. It pivots on a methodological foundation of qualitative inquiry and community-based participatory research (CBPR). Both of these research approaches have much to offer community programmers. Qualitative research is increasingly being used in health service program and policy research. Its methods are useful in generating knowledge about social processes, cultural knowledge, and people’s understandings of their everyday lives (Pope & Mays, 1999; Strauss & Corbin, 1998). As such, it is ideal for designing effective programs for communities through a systematic process of inquiry embedded within historical, political, social and cultural contexts. The qualitative research design used for HYCUP was informed by constructivist, interpretive approaches (Guba & Lincoln, 2005) based on the co-construction of knowledge. Increasingly, public health problems are being recognized as complex and in need of comprehensive and participatory approaches to research and interventions, especially in the face of glaring health inequities (Israel et al., 2005). For community programming, CBPR strategies complement qualitative techniques and push beyond the theoretical and empirical realms of academia to meaningfully involving
community representatives in the design of research that strengthens effective ‘real world’ programs.

In keeping with the principles of CBPR, various methods were used to enhance community involvement as part of HYCUP. For example, the initial needs assessment was informed by a Community Advisory Group consisting of participating children, guardians and healthcare and social service providers (Fielden et al., 2006). Members of this group provided feedback on research goals and focus group scripts, attended a training session on facilitation skills, assisted in the delivery of focus groups, and debriefed with researchers/facilitators regarding findings. Participants and partners were invited to participate in all phases of the research. In one instance, an abstract was co-presented with researchers and a child and parent participant dyad at a national conference. The later phases of the research were more researcher and theoretically driven (i.e., literature review, expert interviews, and community consultations). However, community partners were regularly invited to co-author abstracts and publications, and to provide feedback on the project design and the materials produced.

**Initial Partnership Formation and Identifying the “Community”**

In the province of British Columbia (BC), there are approximately 40 children living with HIV, over half of whom have reached adolescence and young adulthood (Alimenti et al., 2003; Fielden et al., 2006). In BC, as in other provinces across Canada, there is not an established geographic or organizational ‘community’ of perinatally-infected young people specifically although some will interact with each other via their clinical or community family-oriented services. The Oak Tree Clinic (OTC) was established in 1994 in response to
the growing number of HIV-infected families in the province of BC. It is the only tertiary care facility for women and children in the province and has a multidisciplinary team of professionals (Kent, 1996). At the time of the HYCUP research (2002-2007) the OTC had a core clinical staff of infectious disease physicians (obstetrics and pediatrics), a dietitian, a social worker, pharmacists, nurses, and administrative support staff. In terms of social or educational programs, there are a few community-based organizations (CBOs) targeting HIV-affected families, with both HIV-infected and HIV-uninfected children who participate in primarily recreational programs (e.g., a yearly camp). The community in this research was not defined geographically, but as a “unit of identity” (Lantz et al., 2005) and it went beyond the HIV-infected children and young people themselves to include guardians/caregivers, their healthcare and social service providers, academics and other ‘experts’ in the field of adolescent HIV care. Also, due to the dispersed and isolated nature of the families and some of their providers, methods were used that would help in building community such as focus groups and community meetings.

In 2002, the primary researcher (author) approached the HIV specialist team at the Oak Tree Clinic to undertake a collaborative and participatory community-based research study concerned with the needs of older children and adolescents living with perinatal HIV in the province of BC. From these initial discussions, the conception and design of the initial needs assessment were formed. After the needs assessment was complete and, recognizing the dearth of information on existing effective programs for similar populations, additional

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8 According to Israel and colleagues (1998), the term “community” may represent people who have a shared identity either through geography, political affiliation, culture, race, or ethnicity, faith or religion, sovereign tribal nationhood, institutional connection such as schools or workplaces, or other shared identification with a group.
funding was sought to develop the partnership and program model for the HIV-positive children in the province who were quickly becoming adolescents. A development grant of $49,000.00 was obtained from the Canadian Institutes of Health Research (CIHR) forming a research partnership between AIDS Vancouver (a local CBO)\(^9\), researchers from the BC Centre for Excellence in HIV/AIDS (a local HIV-specialized research centre), and researchers from the University of British Columbia. With the support of this research grant the HYCUP Initiative was formalized. This CBPR partnership project, established in early 2006, was developed and continues to be supported through ongoing dialogue between the clinicians, community organization representatives, and researchers. The rationale for this research arose from the lack of best practices research and community models within both Canada and throughout the world affecting this population of long-term survivors of perinatal HIV-infection. The subsequent phases of the research built on the initial needs assessment, illustrated in Figure 3.1 and described below.

**Needs Assessment**

In 2004 a qualitative needs assessment was completed with older children, family members, and social and health care providers to examine strengths, gaps, and possibilities for programs/interventions with this group of HIV-positive young people in BC. The methods and results are described in detail elsewhere (Fielden et al., 2006)\(^{10}\). In brief, the needs were assessed using a participatory qualitative study conducted through a combination

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\(^9\) AIDS Vancouver delivers services to an active caseload of over 1800 individuals and families living with HIV/AIDS. The case management program addresses clients’ complex health needs through care coordination, advocacy, psychosocial support, and home-visiting. It remains the only community-based AIDS case management program of its kind in Canada. In collaboration with other community and clinical partners, they implemented a family home visiting program, providing holistic support and care to children and families infected with HIV.

\(^{10}\) This reference refers to published version of the research presented in Chapter 2 of this dissertation.
of focus groups and interviews involving HIV-positive children and adolescents ranging from 9 to 16 years old (n=10), family members/guardians (n=11), and 11 of their healthcare and community service providers. The focus group methods for the children were modified to include visual techniques through creating collages. Issues highlighted in this needs assessment included a lack of youth-specific, social and community programs to assist this population in their transition to adolescence and adulthood. As part of the study, participants collectively suggested strategies that involved providing peer support and education to the children and youth with perinatal HIV infection as well as family support services, professional services, and educational programs to address issues of sexual health, mental health and social stigma. The children and youth who took part in the needs assessment identified wanting more adolescent programs with recreational components, integrating a sense of fun and interaction among their peers.

**Literature Review**

A literature review\(^{11}\) was later conducted, providing a synthesis of existing empirical, theoretical and community-based literature regarding programs and/or interventions relevant to the psychosocial-, health- and quality-of-life-related needs of adolescents living with HIV in resource-rich countries. Methods included searches of seven health-related electronic databases and hand-searching to locate articles including key terms related to intervention, programs, and/or services targeting HIV-positive youth. The review located 46 articles describing 27 unique youth programs involving young people who were living with HIV, and extracted information regarding characteristics of both the studies and the programs that were assessed such as journal sources, study design and findings, and program settings and

\(^{11}\) The literature review is described in detail in Chapter 4 of this dissertation.
staffing. It also identified gaps in the literature which make it difficult to draw conclusions about core elements necessary for successful delivery of effective programs to this population of young people. The review concluded with recommendations for rethinking the “evidence” necessary to inform real-world program design, implementation, and evaluation. These included encouraging the integration of studies that use both qualitative and quantitative methodologies, and calling for further intervention research into secondary prevention programs for HIV-positive adolescents.

**Expert Interviews**

An exploration was undertaken to uncover core elements of successful programs for HIV-positive adolescents as identified by experts in the field of HIV and Adolescent Health\textsuperscript{12}. Informants were purposively selected by virtue of their training, experience, and expertise. In-depth interviews were conducted by telephone with a total of 15 experts, the sample consisting of researchers, clinicians, and program directors (4 Canadian, 7 American, 2 British, 2 Australian). These experts were asked to reflect on their programming experiences and to identify core elements for programs targeting HIV-positive adolescents. Ten domains of programming emerged from the data indicating that programs should be: accessible, ethical, collaborative, comprehensive, context-driven, youth-centered, sustainable, appropriately staffed, youth-friendly, and normalizing. These categories and their subcategories formed a model to encourage dialogue about programs for young HIV-positive women and men and to illustrate the factors that may be considered during the process of program development and delivery.

\textsuperscript{12} The elements of successful programming identified by the experts are described in detail in Chapter 5 of this dissertation.
Environmental Scan and Community Consultations

Over the course of two years, a series of consultation sessions were held with a broad cross-section of community stakeholders within Canada. To gain a better understanding of services and programs for perinatally-infected adolescents, an environmental scan was conducted to identify existing clinical and community-based programs for young people with perinatal HIV-infection. This assessment included informal in-person and telephone interviews (n=26) with representatives from fourteen major centres for HIV pediatric treatment and social services across Canada. Participants included clinical staff and program managers. Questions focused on issues related to existing programs, relevant challenges and successes, current population needs, and recommendations for future areas of program development. Notes were maintained and sent to consultants for verification and were analyzed through grouping and comparing participant responses. The consultations demonstrated that existing clinical programs provide multidisciplinary specialized care to HIV-infected children and their families. Community programs provide additional material, recreational, therapeutic and educational programs. However, these services are few in number and limited to major urban areas. Participants consistently identified the need to create culturally-appropriate and youth-friendly HIV programs that integrate the complex psychosocial factors affecting these perinatally-infected young people as they mature into adulthood. Participants also agreed that programs must work to further address issues pertaining to adherence to HIV medication, disclosure of HIV status, stigma, sexual health and transition and continuity from pediatric care into adult-based clinical services. Additionally, several local funders and executive directors of community-based organizations

13 These consultations are not represented elsewhere in this dissertation as they were led by community agency representative working in partnership with the HYCUP Initiative. The results have been reported as a conference abstract (Sargeant et al., 2008).
were approached and asked to identify issues pertinent to program funding, sustainability and the potential for integrating perinatally-infected youth into existing community programs. Responses were positive overall and included factors such as a built-in sustainability plan, ongoing evaluation, the development of social enterprise, and partnership creation. This last step served to provide direction for programming and build stronger connections to local organizations as well as disseminate information about the research partnership’s goals and objectives into the community.

**Knowledge Translation**

A key feature of the HYCUP Initiative was the commitment to ongoing translation of knowledge to community agencies and project partners throughout the course of the research (2002-2007). In addition to disseminating the HYCUP research model and findings at several national and international conferences and through producing peer-reviewed journal articles, HYCUP employed several more community-oriented strategies for knowledge translation. These included: shared coordination of the project; the dissemination of community reports; and a community meeting with key stakeholders.

**Shared Coordination**

One of the key strategies employed was the hiring of a “community learner” into the position of research coordinator. This participatory research strategy has been employed successfully in other community-academic partnerships (Fielden et al., 2007). The participation of the community learner is intended to develop the research capacity of academic and partner organizations (i.e., their ability to receive and use research tools and results). This position existed in the project from 2006 to 2008 and was filled by two women.
who were leaders in the HIV community and employed at YouthCo AIDS Society, Canada’s first youth-driven organization leading the way in HIV programs for young people through HIV peer education, support, and shared leadership. The existence of this position allowed informal dissemination of findings through the everyday activities and interactions of staff at community-based organizations.

**Community Reports**

Several community reports helped to disseminate the research results to various stakeholders. The findings of the needs assessment were compiled in a community report (Appendix B) which was disseminated widely to HIV agencies in BC, local health service managers, HIV researchers around Canada, and research participants. A separate pre-tested child-friendly report of research findings was prepared and distributed to the child and adolescent participants (Appendix C). The findings of the literature review, community consultations, and expert interviews were compiled in a 7-page leaflet that was circulated to community partners, research participants, and during conference presentations (Appendix D). A summary of the project was also prepared and disseminated through the Canadian AIDS Society newsletter, a free national HIV resource (Fielden, 2007).

**Community Meeting**

The research culminated in a community meeting, held in the fall of 2007 at a local AIDS Service Organization. Project materials and consent forms were circulated to potential participants who were purposively selected for their involvement and experience with HIV-infected adolescents in BC. Participants in this meeting included key decision-makers (e.g., ASO Executive Directors, HIV-specialist healthcare professionals) in clinical and community
service organizations for HIV-infected children, families, and youth in the province of BC.\textsuperscript{14} A formal presentation was delivered (by the primary researcher) that outlined the research results of the various phases, including three proposed service models for future programs targeting the needs of adolescents with perinatally-acquired HIV. These models were based on popular existing service models, located through the peer-reviewed and grey literature. The discussion that followed was facilitated by an external consultant and aimed at developing consensus regarding a future direction for programming for the target population. The principle conclusion from this meeting was the need and willingness of stakeholders to move forward with a new community social program for HIV-infected and HIV-affected adolescents in BC. The proposed program included providing individualized support through case-management services to these two groups of adolescents and initiating youth-friendly group activities, recreation, education, and support through a yearly peer-led youth skills symposium. This shared goal formed the basis for the continuation of the HYCUP academic-community partnership, the development of a new Community Advisory Board, and the collaborative development of both research and community program funding proposals (refer to Appendix E for an example proposal summary).

\textbf{Lessons Learned from the HYCUP Partnership}

According to Sork (2000): the \textit{technically-capable planner} is able to judiciously select and thoughtfully apply various skills and techniques that are appropriate to program goals and context; the \textit{politically-aware planner} is sensitive to the relationships, power dynamics, ideologies, and interests of program leadership and staff that may have an impact

\textsuperscript{14} Young people living with perinatally-acquired HIV were not included in the meeting due to difficulties with accessing the population, Institutional Review Board requirements, and ethical concerns about power differentials and tokenism.
on program development; and the **ethically-responsible planner** recognizes moral questions and issues embedded in planning while confronting conflicting moral positions as part of the planning process. Figure 3.2 summarizes the methodological aspects of the HYCUP project in terms of the technical, ethical, and socio-political domains. These elements are grouped according to what the author perceived as ‘best-fit’. However, the categories are not mutually exclusive and overlap as illustrated by the intersecting loops. For example, using community-based strategies may be ‘social-political’ in that they enhance buy-in and strengthen partnerships but they also form the base for the ‘technical’ application of research methods and may arguably be seen as more ‘ethical’ when compared to more traditional epidemiological research approaches because researchers are accountable to communities\(^{15}\).

The **technical** aspects of the development processes included the design and planning of the research approach such as identifying the problem the program is to address, the goals and research objectives, forming partnerships and Community Advisory Committees, selecting of participants and carrying out proposed research processes, coordinating the activities (such as meetings), developing and submitting funding proposals, staffing, budgeting, and disseminating of information in various forms. The **social-political** elements of the program development included research to enhance community and partner participation and buy-in (e.g., using community-based participatory processes, and requesting partner and participant feedback on the research design and implementation), to mediate potential partnership conflicts (e.g., hiring external facilitators for key meetings, using democratic decision-making processes, acknowledging power differentials and group

\(^{15}\) CBPR practices aim to improve the health and well-being of communities involve through addressing their needs, building community capacity, and increasing community power and control over the research process (Israel et al, 1998).
dynamics), and to increase feasibility of program implementation (multi-stakeholder involvement including key decision-makers involved in program management and funding). Processes used to address ethical issues included obtaining ethical approval from relevant institutional review boards (IRBs) (Appendix A), emphasizing voluntary and consensual involvement of all participants including minors, being transparent (e.g., circulating results, proposals and meeting minutes to participants and partners), and prioritizing the representation of multiple stakeholder voices in the program development and research findings. Through the development of the HYCUP partnership and the CBPR processes involved, several technical, sociopolitical, and ethical challenges and facilitators arose.

The Technical

Community-based participatory research principles recommend the participation of the community in every stage of the research including the research design, implementation, and dissemination (Lantz et al., 2005). Likewise, community program planning models for health also recommend working closely with communities to design effective programs (Green & Kreuter, 2005; Sandler, 2007). Despite good intentions, collaborations of this nature can prove impractical and burdensome for some participants. This approach assumes that people are able and willing to commit to a high level of involvement. It ignores the reality that people who work in non-profit community organizations are often running multiple programs at once and are spread thin with meager resources. It ignores that clinicians may not be able to justify attending frequent research meetings or conducting research tasks that take them away from their time with patients. Collaborative processes may also cause protracted timelines that are incompatible with timely responses to solving community problems and typical community and academic funding practices. For example,
community researchers and programmers often respond to calls for proposals that have fast approaching deadlines and to priorities that may change relatively quickly with political climate or new topics of interest.

One of the major technical challenges of the partnership was the time required to develop the relevant empirically and theoretically-informed program model. The issue of time and resource commitment has been frequently discussed by community-based researchers (Lantz et al., 2005). The timeline of program development spanned approximately five years due to the research-based planning process, transitions in the community (e.g., staff turnover, CBO relocation), and the management of the multiple partners. Working in cooperation with many stakeholders also required extensive research documentation and communication. For example, each group (children, family members, healthcare and service providers, ‘experts’) required personalized invitations to participate, individual consent forms, and variable information dissemination techniques (e.g., appropriate to age and literacy level), all of which took extensive time to prepare and revise. Soliciting and incorporating feedback from partners and participants, although enriching and strengthening to the research and planning, also required a large time commitment. Additionally, partners and participants in HYCUP were not situated in the same locations but were spread around the city of Vancouver and in some cases, around the province. This made in-person meetings expensive and group meetings difficult and time-consuming to coordinate. As a result, much of the feedback on the research process was solicited individually via emails or phone conversations and not through a consensus-building group process. Sharing and using existing resources such as meeting space and institutional
equipment facilitated the technical aspects of planning as did the obtaining the CIHR funding that allowed for the hiring of coordinators.

We conclude from the HYCUP experience that collaborative partnerships may be plagued with logistical problems in terms of bringing together stakeholders and making sure that various partners have input into the planning process. Programmers have to work within the reality of available resources and conflicting schedules and priorities of stakeholders. The result is often that only select partners and participants will be available and willing to provide feedback at various stages of the research process. As opposed to participation at every stage of the research, it may be necessary for program planners and researchers to be satisfied with a process that adheres to the CBPR philosophy and is as ‘participatory as possible’, giving people flexibility, choices, and options during the project evolution. In addition to the challenges experienced with bringing decision-makers, community agency representatives, and healthcare professional to the table, meaningfully engaging participants from vulnerable populations such as the HIV-infected children and their family members can prove difficult because of the business of their lives. Young people may be involved in school activities, extracurricular groups, work, and have full social lives. These commitments combined with obligations such as regular medical appointments and/or dealing with sickness within the family may take priority over any type of participation in research activities. This reinforces the need for programmers to remain flexible in defining “participation” and to provide substantial incentives/payment to research partners and participants who are not compensated for their participation through their organizational affiliations.
The Socio-political

Complicated power dynamics are always present and need to be acknowledged during the processes of research partnerships and program planning (Frankish et al., 2002; Israel et al., 1998; Wilson & Cervero, 1996). These may include but are not limited to power differences existing on the basis of organizational and professional (resources, reputation, status) and personal (ethnicity, gender, socioeconomic status) characteristics. This may be especially true when trying to work collaboratively with those individuals who are marginalized as a function of being members of vulnerable populations. Sandler (2007) discusses how power operates within communities, between organizations, within organizations, between community groups, between organizations and funders as well as between academic institutions and communities. The literature contains many recommendations regarding working with vulnerable populations such as community participation, cultural and linguistic competence and comprehensive services (Flaskerud & Winslow, 1998). Communities may have considerable distrust of research due to negative prior experiences with research and/or authority in general (Cheadle et al., 1997). Trust-building and power sharing are therefore of paramount importance in partnership and community-based research.

The HYCUP partnership provided a vehicle for collaborative program planning with input from community members, service providers, and researchers. It enabled what Habermas conceptualized as “communicative spaces” which are “open and fluid associations” (Kemmis, 2001, pp 100) embodied in social networks where issues and problems are discussed and opinions are shared as part of an interactive democratic process (Kemmis, 2001). However, two main challenges were identified during the planning process
that may be considered ‘socio-political’ in nature. Firstly, working with multiple and multidisciplinary community partners and participants introduced many layers of power and accountability. Participants in the various stages of the research included HIV-positive children, their parents and other legal guardians, local community service providers, physicians and allied health professionals, researchers, and international clinical and academic HIV specialists. There were significant differences between some of the groups in terms of age, race, gender, income, education, and social status. Consideration of power dynamics often influenced the methods used to collect information and who was able to participate. For example focus groups were chosen for children in part to dilute the adult researcher-child power differences. Also, biological caregivers and foster parents were placed in separate focus groups due to differences in social status and research partners’ concerns about blaming attitudes directed towards biological caregivers. Careful consideration and training went into the facilitation of focus groups and research meetings in an attempt to mediate some of the complex power issues and ensure a more egalitarian, democratic decision-making process. However, as Sandler (2007) points out in his discussion of power in community-based practices, these collaborative efforts have a minimal impact on the structural violence that effects communities and divides the various stakeholders in the partnership.

A second and related socio-political issue was that access to the vulnerable population (i.e., the HIV-infected children and adolescents) was controlled by various ‘gatekeepers’. Due partly to the stigmatizing nature of their disease and the professional ethics in health services, the identities of the children are carefully guarded by those who know and work
closely with them. Gaining the approval of these “gatekeepers”, defined generally as those attempting to safeguard the interests of others (Greig & Taylor, 1999), required negotiations at multiple levels. The more gatekeepers that exist (in this case, parents/guardians, healthcare professionals, and government bodies that regulate foster care) and the more diverse their backgrounds, the more restricted research activities become which, in turn, affects the ability to develop meaningful rapport with the participants and the quality of the research results. Access will depend on rapport-building and rapport-building will depend on the values, skills, research orientations, and social and professional standings of all parties involved. Researchers need to build trusting collaborative relationships and seek permission of gatekeepers who are involved with HIV service provision – such as clinical staff at specialized clinics, or non-governmental organizations. HYCUP trust-building activities included: researchers partnering with professionals and service providers trusted by the other community members; regular community and partner consultation; participatory research methodology seminars for partners; transparent methods; and sharing results and incorporating community and partner feedback. Accessing HIV-positive adolescents for the needs assessment was accomplished through third party recruitment via the Oak Tree Clinic. A trusted staff member\textsuperscript{16} approached potential participants and explained the research to the children and family members, emphasizing the voluntary nature of participation. This same staff member also contacted legal guardians to obtain parental consent. The researcher only gained access to participants after this process was completed and was then only given the first names (or pseudonyms) of participants. Strategies such as these used to maintain

\textsuperscript{16} This staff member had known most of the children for their entire lives and had gained the trust of family members over a long-standing relationship.
confidentiality increased the comfort and ease of working in partnership with various stakeholders and vulnerable populations.

**The Ethical**

A major consideration in this research process were the ethical issues associated with working with vulnerable populations of children, youth, and their family members. Working with minors presents specific ethical challenges that are both similar and different from other vulnerable populations (Christensen, 2002). Ethical considerations for conducting research with HIV-positive children are also not unlike those that one might consider in research with any group of children and may be informed by guidelines such as those put forth by Alderson in 1995 (Christensen, 2002) the Tri-Council Policy Statement (CIHR, NSERC, & SSHRC, 2005), and the UN Convention of the Rights of the Child (United Nations 1989). In research with HIV-positive children ethics are highly embedded in the dynamics between family members, children, healthcare providers and the outside world. Coinciding with the provincial legal age of majority, parental/guardian consent was required for research participants under 19 years old, and assent was obtained from all children. Despite the existence of guidelines, ethical dilemmas arose from the project, especially surrounding the issue of protection.

One of the persisting and unresolved problems in involving children in research is in the defining of a “child” or “adolescent”. This is relevant insofar as it is these definitions that make children subjects of adult control and protection and may limit children’s ability to participate in research. Levine states in her book Harmful to Minors: “there is no distinct moment at which a person is ready to take on adult responsibilities, nor is it self evident that
only those who have reached the age of majority are mature enough to be granted adult privileges. People do not grow up at 16, 18, or 21, if they even do” (Levine, 2002, pp 88). Childhood is socially and historically constructed through ideas of innocence (e.g., Rousseau), evil (e.g., Freud), and incompleteness (e.g., Piaget) (James et al., 2005). It has been legally defined by age-related privileges (e.g., ages for driving, voting, consuming alcohol, etc) and ages of majority which may vary within and between countries. It has largely been operationalized by the field of developmental psychology which distinguishes “normal” development from “abnormal” and delineates at what ages children should pass through stages that permit them to become more and more like adults. HIV-infected children in the HYCUP project were often referred to as “sheltered” by partners and some presented with developmental delays. With children who potentially have these challenges, it is even more difficult to ascertain what level of participation is ethical and appropriate. These ethical issues become obscured in the case of HIV-infected children due to the multigenerational effect of the illness and the possible confounding issues of parents/guardians acting in their own interest (e.g., protecting their own identities) as opposed to that of the child. Some strengths of HYCUP regarding ethical issues were: the participatory nature of this project (e.g., it involved young people and family members in the design of interview scripts); the input of multiple gatekeepers on research design and materials; and the adult stakeholder’s sincere interest in the well-being of the young people.

The issue of protectionism may legitimately prevent harms but may also limit a young persons’ ability to self-determine and participate in a process intended to be empowering and provide opportunities for collective action. All stakeholders participating in
planning, including researchers and partners, need to reflect on their social and professional positions and their responsibility to keep the children ‘safe’ perhaps at the expense of enabling the children’s personal agency. Dissemination of research results is a critical time to consider ethical responsibilities as the researchers make public their interpretations of the children’s experiences or involve the participants themselves in sharing the findings (Cree et al., 2002). For example, including research participants in conference abstracts and publication will compromise confidentiality, potentially leading to harm. Considerations will vary depending on the type of research being conducted but issues of coercion, reciprocity, and consent/assent are paramount considerations given the multiple vulnerabilities (and strengths) of HIV-positive children and adolescents. Unfortunately, ethical considerations have led to more questions than answers – questions surrounding issues of enabling voice and representing children, aiding and abetting HIV stigma, perpetuating power relations, and the overall harms and benefits of the research process for the researcher, the gatekeepers and the children themselves. However, the act of asking these questions contributes to more reflexive community-based participatory research practices. Research such as this illustrates the ethical struggles for researchers who wish to conduct empowering CBPR research while being conscious of the vulnerability and power differences that exist between the multiple stakeholders in the planning context.

**Lessons Learned**

A number of recommendations were born out of the process of developing the partnership and implementing the various stages of the HYCUP Initiative. These may inform
those hoping to develop or currently struggling with partnerships for program planning and community-based research.

- Program planning is enhanced through meaningfully engaging various groups of stakeholders and through the development of community-academic partnerships that build on existing community knowledge and research evidence. Community-based participatory research processes complement these goals but it is important to remain flexible and create a process that is ‘as participatory as possible’, providing options and choices for participants and partners.

- Creating new partnerships requires patience, commitment, and an integration of research into existing community processes and community into existing research processes. Participatory planning is time-intensive but creates new synergies that open additional avenues for innovative public health research.

- A multistep, iterative, ethical process that involves continually revisiting the possible harms and benefits to all stakeholders is necessary when working with vulnerable populations such as young people. This should involve collaborative and reflective/self-critical practice while developing, implementing, and evaluating programs.

- Academic and clinical institutions continue to support social hierarchies which will inevitably challenge planners and researchers who wish to merge these social worlds with community-based organizations and vulnerable community members. For partnerships to survive, strategies such as conflict models need to be developed to acknowledge and deal respectfully with the expectations and diverging interests of the various partners.
- Current government research priorities are evolving to encourage research partnerships and community-based practices. However, these need to continue to shift towards providing research and planning resources for supporting community intervention development, implementation, and long-term sustainability.

- Knowledge transfer and translation is enhanced through the organic process of partnerships and through using multiple strategies within the community and academic sectors. Some key strategies may include paying community leaders to participate in research, creating lay and academic publications, and coordinating community meetings.

These recommendations have arisen through a novel multi-stakeholder research partnership including adults and young people, family members, community service providers and researchers at various stages. These recommendations bring together issues that have been identified by other planning and CBPR practitioners working within varying contexts and with a multitude of vulnerable populations with unique circumstances (Israel et al., 1998; 2001; Potvin et al., 2003; Sork, 2000). These commonalities strengthen the call for more support, resources, and capacity-building in participatory research practice. This paper confirms what others have reported through a reflexive analysis of partnership processes and “messiness” using the planning lenses of the socio-political, ethical, and technical.
Conclusions

This paper describes the HYCUP case study that merged community-based partnership research with planning health promotion programs with a vulnerable population of young people. It elaborates on some of the ‘people work’ of program planning through discussing relational and contextual factors that both strengthen and limit program development.

The HYCUP Initiative sought, through various forms of collaboration, to create a program model targeting the needs of adolescents with perinatally-acquired HIV in British Columbia, Canada. Despite global HIV media attention and ongoing prevention and treatment efforts in communities, adolescents living with perinatally-acquired HIV remain socially and economically marginalized, and are relatively ‘hidden’ in terms of HIV policy and programming. Community-based research partnership such as this are ideally placed for raising awareness regarding this population of young people and informing new strategies for reaching vulnerable groups with research and programs that promote health. In sharing the lessons learned from such partnerships, researchers, programmers, and other decision-makers can begin to adapt successful strategies and address difficult questions concerning technical, sociopolitical, and ethical aspects of program planning. These questions include: how can we produce evidence-informed community programs, how can these programs and partnerships be created and sustained over time, how can we best build and maintain trust within partnerships, and how can we attend to historic wrongs and shift power towards traditionally marginalized groups?
Figure 3.1: Illustration of research phases involved in program development for the HIV/AIDS Child and Youth Umbrella Program (HYCUP) Initiative
Figure 3.2: Elements of CBPR processes using a framework of the technical, the social-political, and the ethical

Technical
- Choosing CBPR research methodology
- Formation of Community Advisory Committees
- Coordinating meeting logistics and timelines
- Choosing sampling techniques
- Obtaining funding
- Hiring and training of project staff
- Providing incentives to project participants
- Implementing and research phases, and methods
- Recording research data and conducting analysis
- Information Dissemination: writing reports, articles, meeting/conference presentations

Ethical
- Obtaining IRB Approvals
- Obtaining informed consent (adults and parental/guardian/participant)
- Obtaining informed assent from children
- Emphasizing voluntary involvement
- Inclusion of multiple “voices”
- Creating safe and respectful environments for participants
- Being transparent with research and planning objectives and processes

Social-Political
- Creating feedback information loops
- Using democratic decision-making processes
- Hiring external professionals for facilitation of key meetings
- Involving multiple stakeholder
- Forming an academic-community partnership for sharing skills and knowledge
- Using community-based participatory research processes to build trust
- Involving funders and decision-makers
- Considering and managing power dynamics in group/meeting planning

Figure 1: Elements of CBPR processes using a framework of the technical, the social-political, and the ethical
References


Canadian Institutes of Health Research (CIHR), Natural Sciences and Engineering Research Council of Canada (NSERC) & Social Sciences and Humanities Research Council (SSHRC) of Canada (1998 with 2000; 2002; 2005 amendments), *Tri-Council Policy Statement; Ethical Conduct for Research Involving Humans*.


Chapter 4: A Review of Intervention and Programming Articles Targeting Young People Living With HIV: How Can Evidence Inform “Prevention For Positives” Youth Programs?17

Introduction

Behavioral, social, and community interventions can enable people to adopt and maintain behaviors that substantially reduce their risk of communicable diseases and improve their quality of life. An important step in decision-making regarding allocating funding and for developing high quality interventions is gathering and evaluating the existing evidence regarding program characteristics, effectiveness, and needed resources for the delivery of interventions. This information is crucial because service providers and funders should begin with a clear understanding of the core elements of successful programs, the potential positive and negative impacts on risk behaviors, and the ability of this knowledge to be transferred to programming in various contexts (McKay, 2000).

It is estimated that nearly half of new HIV infections occur among people under 25 years old (UNAIDS, 2008). Many cases diagnosed in adulthood result from an infection during adolescence and, with rising rates of HIV being detected in adolescence, youth interventions are increasingly important (Rotheram-Borus et al., 2000). There is a substantial body of literature to support high prevalence of sexual activity and HIV risk behavior in adolescents in resource-rich countries (e.g. North America, Western Europe) (Boyce et al., 2003; Eaton et al., 2006; PHAC, 2007; Santelli et al., 2000; Wellings et al., 2006). Even

17 A version of this paper will be submitted for publication. Fielden, S.J. A Review of Intervention and Programming Articles Targeting Young People Living With HIV: How Can Evidence Inform “Prevention For Positives” Youth Programs?
though many HIV-infected people adopt protective behaviors, studies have indicated that many youth still engage in high risk activities (Lightfoot et al., 2005; Rotheram-Borus et al., 2001b). From a public health perspective, HIV-infected young people are in need of effective interventions to prevent transmission of the virus and re-infection with potentially resistant strains, as well as promote their optimal long-term health.

Young people who are HIV-infected may differ substantially from the general population and those youth who are considered ‘at risk’ for HIV infection (Hein et al., 1995; Kennedy et al., 2000; Rotheram-Borus & Miller, 1998). Although some HIV-infected and ‘at-risk’ uninfected youth may have similar risk factors in terms of demographics or other determinants of health, it is reasonable to assume that once a young person acquires HIV, different considerations and environmental factors govern their behaviors. For example, fear of becoming HIV infected is no longer part of the decision-making process whereas altruism may dominate behavioral motivation (Luna & Rotheram-Borus, 1999). Perceived risk or vulnerability is a central construct in many of the major health protective/risk reduction and health promotion behavior models such as the Health Belief Model (Janz & Becker, 1984), and the Theory of Reasoned Action (Ajzen & Fishbein, 1980) (Gerrard et al., 1996a; Gerrard et al., 1996b). Therefore, programmers cannot assume that the same HIV risk reduction interventions that have been proven effective with at-risk youth can be equally applied to youth already HIV-infected. Despite recent calls to promote “prevention for positives” (CDC, 2008; Shriver et al., 2000), there is currently a dearth of evidence regarding intervention efficacy and effectiveness with youth post HIV-infection. The goals of these
Interventions may vary but generally will focus on promoting health and wellness through decreasing risk behaviours and improving psychosocial outcomes.

From a policy and programming perspective, decision-makers cite research findings, and in particular systematic literature reviews, as one source of information when deciding or justifying which programs they support (Dobbins et al., 2007; Dobrow et al., 2004; Fox, 2005). They look to researchers not only to provide the studies but also to provide clear direction in translating this knowledge in the implementation of programs with the long-term goal of improved population health outcomes (Dobbins et al., 2007). One disadvantage of this shift towards ‘evidence-based public health’ is that areas of study where limited research is available, for example on “hidden populations” (Bell et al., 2003b), may be neglected when it comes time to develop and fund interventions. Another disadvantage is that literature reviews, especially systematic literature reviews, have been widely criticized by social scientists on account of their privileging of evidentiary sources that spring from traditional epidemiological or clinical study design, the ‘gold standard’ being the randomized control trial (Dixon-Woods et al., 2005; Kemm, 2006; Sandelowski, et al., 2007a). Moreover, stakeholders are increasingly recognizing that the notion that there is a ‘best solution’ ignores the complexity of the decision-making processes and the importance of context in policy making (Dixon-Woods et al., 2005; Dobrow et al., 2004; Kemm, 2006). Investigators are calling for inclusion of various methodologies and evidence in order to inform decision-making, including qualitative forms of research and expert judgment (Dixon-Woods et al., 2001; Jack, 2006; Kemm, 2006; Sandelowski et al., 2007a).
The purpose of this review is to describe and critique the existing body of peer-reviewed literature readily available to health researchers and decision-makers to inform health-related programs for youth post HIV-infection. Given that what constitutes ‘evidence’ is still very much up for debate; this review uses a narrative summary process whereby it provides a descriptive “account of the evidence” (Dixon-Woods et al., 2005). In light of the problematizing of valuing evidence, this review approaches the body of literature addressing interventions for HIV-positive youth as a body consisting of authors providing multiple and multi-methodological perspectives to creating successful interventions. Due to this large variability of studies and the challenges described in the following sections, synthesizing the empirical results was beyond the purview of this paper. The examination of the body of evidence does not pertain to assessing study design or rigour but to what literature is available and how these publications might better lend themselves to synthesis and analysis in order to illuminate pertinent programming issues for youth living with HIV. For the purposes of this study “youth” includes adolescents and young adults and is defined as those aged 13 to 25 (United Nations, 2008).

Methods

Relevant published literature was located by searching seven electronic databases for articles published from January 1990 to December 2007. The databases examined were: MEDLINE, PsychINFO, CINAHL, Academic Search Premier, and Social Work Abstracts. As well, AIDSLINE was searched for relevant abstracts and the authors located were searched for associated full-length manuscripts. Finally, the Web of Science citation index was used to cross check the authors to identify additional relevant articles.
The search was performed by combining specific search terms using Boolean logic and truncation in order to capture programs for HIV-positive young people. This combined terms and versions of: living with HIV, HIV-positive, HIV-infected, youth, young person, teenager, adolescent, program, service, intervention, case management, outreach, model, and framework. The initial keyword database search yielded 3064 articles. When limiters were placed, 589 of these remained. The limiters used in the literature search were: human, English Language, years (1990-2007) and peer-reviewed articles. When this search was further limited to searching only abstracts as opposed to “all fields”, 207 abstracts remained for review.

Informed by the work of Shoveller & Pietersma (2002), the criteria for selection are categorized in Table 4.1. These criteria were applied to the remaining 207 abstracts. After ineligible and duplicate abstracts were removed, 95 articles describing program models, services, or interventions targeting HIV-positive adolescents and youth were selected for full-text review. After these were read in detail by the author, 46 articles remained eligible for the review. Samples consisting of non-youth participants (e.g., program administrators) were included if the program and results described explicitly targeted adolescents and youth. Reference lists from the 46 articles selected for inclusion were further searched for relevant article titles. Publication titles of 34 relevant journals were also scanned from the final year (2007) in order to account for any lag time in journal indexing (Lyles et al., 2007). However, these last two steps yielded no new information.
Data from the remaining 46 articles was organized and synthesized in matrices following procedures outlined by Gerrard (1999). Information about the goals of the articles and intervention characteristics was extracted. This included characteristics of the populations served, location and settings, and outcomes/lessons learned of program evaluations. Interventions/programs were grouped by category of individual, group, and/or community level interventions. In attempting to ascertain “what works” and “what doesn’t work” in terms of developing programs, barriers and facilitators were extracted from program descriptions, results, and conclusions. However, the barriers listed and the facilitators did not necessarily reflect empirical outcomes presented in the evaluations but more often reflected the authors’ expert opinion.

Results

Of the 95 articles identified as potentially relevant, three were excluded because they did not explicitly target adolescents and/or youth, four were excluded because they did not specifically include HIV-infected youth, eight were excluded because they were commentaries/reviews/editorials, one was excluded because it was not from a resource-rich country, and one was excluded because it only presented a program description with no assessment component. The majority excluded (32) did not include sufficient details about a program, service, or intervention to be effectively assessed. This was also the case with the preliminary abstract evaluation whereby the majority of rejected abstracts did not contain any description of an intervention/program/service. Table 4.2 shows the details of the 46 reports included, organized by program/intervention. Some of the articles are not cited elsewhere in the text but are included in the table (Dodds et al, 2003; Futterman et al, 1993; Johnson et al, 2003a; Martinez et al, 2003; Woods et al, 2002a).
programs/interventions. Six of the articles combined programs to draw some comparisons and create shared conclusions. Six did not specify a particular program, although it appeared that four of these were related to the Teens Linked to Care (TLC) or Clean living, Empowerment and Results (CLEAR) program (Elkavich et al., 2006), and the remaining two were independent programs.

**Characteristics of Reports**

These 46 reports were published in 19 different journals. Many of the articles were clustered within the same journal volume with 17 of the 46 published in the *Journal of Adolescent Health*, 7 in *AIDS Patient Care and STDs*, 2 in *Evaluation and Program Planning*, and 2 in *Hemophilia*. Fifteen of these articles were contained in the same two special issues of the *Journal of Adolescent Health*, describing the results of the Special Projects of National Significance (SPNS) which funded 10 HIV youth programs as demonstration projects (Huba & Melchoir, 1998), and the SPNS-funded Adolescent Women and Children Programs (AWAC) findings compiled in a 2003 issue (Johnson et al., 2003b).

Three reports recruited agency staff or service providers at youth centres (Lin et al., 1998; Dilorenzo et al., 1993) and Voluntary Counseling and Testing (VCT) sites (Silver et al., 1998) as respondents, while Stanton (2000) recruited staff members, community leaders, administrative staff, and donors for a qualitative case study of Larkin Street Youth Centre. Eighteen of the reports combined HIV-positive and HIV at-risk youth which permitted the researchers to conduct more sophisticated analyses and to draw broader conclusions but was limiting in that results became less representative of the issues relevant to the needs of HIV-infected youth specifically. Only 24 articles described programs that targeted HIV-positive
youth exclusively. Articles often did not include or specify sub-populations (e.g., by mode of HIV transmission) of HIV-positive youth within their cohorts. For example, only three reports described programs that targeted youth with vertically-acquired HIV directly (Ellis et al., 2006; Funck-Bretano et al., 2005; Weglarz et al., 2005), four others stated that the study populations included only a very small minority of these perinatally-infected young people, three explicitly excluded members of this population, and 35 did not state their exclusion or inclusion. Three of the articles related specifically to the experience of HIV-positive young men with hemophilia as part of a single American research project, Hemophilia Behavioral Intervention Evaluation Project (Brown et al., 2000; Butler et al., 2003, Schultz et al., 2001).

The methodologies and designs of the studies were variable. Only four studies (Lightfoot et al., 2007; Naar-King et al., 2006; Rotheram-Borus, 2004; Song et al., 2006) were designed as controlled and randomized intervention studies. At the other end of the spectrum, five had explicitly qualitative research methodologies (Kennedy et al., 2000; Stanton et al., 2000; Rosenfeld et al., 2000; Rotheram-Borus et al., 1998; Weglarz et al., 2005). Articles described programs and provided some data resulting from quantitative, qualitative, and mixed methods evaluations with variable outcomes including behavioral, psychosocial, client satisfaction, clinical, service use and program retention. Sixteen of the articles indicated multi-site programs/interventions. However, all articles indicating a location (42) were delivered in the United States with the exception of one that targeted a group of adolescents with perinatally-acquired HIV in Paris, France (Funck-Bretano et al.,

19 Please refer to Appendix F for an additional Table providing further details concerning reports including youth with perinatally-acquired HIV specifically.
This review focused on articles that provided some indication of “what works” and “what doesn’t work” in terms of programming elements. Therefore, they all included some form of evaluation: summative, process-oriented, and/or formative. However, results were often limited to superficial demographic information or behavioural outcomes and did not include results related to program quality or successful ‘core elements’ that could be reproduced in other contexts. Evaluations varied from a smaller scale such as Weglarz’s (2005) n=2 case study methodology to Rotheram-Borus’ (1998; 2001a; 2001d; 2004) controlled intervention trials, to multi-site, multi-program structural equation modeling used by the Measurement Group in the case of the 10 SPNS-funded programs across the US (Huba et al., 2000; Huba & Melchoir, 1998). Despite the fact that all the reports were focused on program delivery, only 13 of the 46 reports contained clear statements of the lessons learned or implications for policies/programs in their publications. Also, less than half the articles (21/46) included a clear statement of the limitations of their evaluations.

Summary of Findings

The results from the various reports mirrored the variability in program and evaluation characteristics. This section provides examples of evaluation designs and outcomes from the articles included for review. When demographic information was provided in the articles, it depicted the diversity of the HIV-positive young people accessing programs. For example, among program participants, gay, lesbian, and bisexual youth were represented in high numbers (Remefedi et al., 1998; Rotheram-Borus et al 2001c; Sturdevant
et al., 1998;) as were youth from ethnic minority groups (Sturdevant et al., 1998; Tenner et al., 1998a; Woods et al., 2003). There were many young program participants with a history of substance use, depression, and homelessness (Remafedi et al., 1998; Schneir et al., 1998; Tenner et al., 1998b).

Some of the reports evaluated program effectiveness through intervention trial designs that examined the associations between program participation and risk behaviours or psychosocial variables. Interventions such as the psycho-educational sessions offered in the TLC and CLEAR programs for HIV-infected young people have been shown to effectively reduce risk behaviours, improve coping and emotional well-being (Rotheram-Borus et al., 2004; Rotheram-Borus et al., 2001a; Rotheram-Borus et al., 2001d; Rotheram-Borus & Miller, 1998) and prove cost-effective through the number of averted HIV infections compared with controls (Lee et al., 2005). Rotheram-Borus and colleagues (2004) found that the CLEAR intervention was efficacious in reducing the number of sexual partners, and increasing the percentages of protected sexual acts and HIV disclosure to sexual partners, and that in-person sessions were more successful than telephone sessions. Similarly, the three reports from the Hemophilia Behavioural Intervention Evaluation Project including 10 care sites detailed the development of the intervention and reported its successes through the quantification of behaviour change in participants (Brown et al., 2000; Butler et al., 2003, Schultz et al., 2001). They found that in their sexual health program which included individual counseling sessions, group sessions with social activities, and an intensive group session, safer sexual behaviour was associated with peer support for outercourse, perceived peer support for abstinence, and decreased general emotional distress.
Other reports looked at participant health outcomes of established community programs offering a wide variety of services. For example, in the Larkin residential multidisciplinary care program for HIV-positive youth described by Rotheram-Borus and colleagues (2001c) improvements were seen in participants’ nutrition habits, hygiene and worries about health status but no significant changes occurred in sexual and substance use risk over the first year in the program. Wright and colleagues (1998), in a program that targeted gay, lesbian, and bisexual youth through training, outreach, and peer support services reported trends towards prevention behaviours and improvements in self esteem with decreases in psychosocial distress. Sturdevant and colleagues (1998) found that a program based on an empowerment and the social learning model was effective at increasing AIDS knowledge in the participants, however skills such as condom use did not significantly change.

Few studies examined client views or satisfaction with services. Bettencourt and colleagues (1998) demonstrated that youth used and were largely satisfied with the many services offered (e.g., counseling, housing, alternative health care, medications, vocational training, case management) as part of the Bay Area Young Positives Program, a peer-driven program meant to empower and support HIV-positive youth. They found that members enjoyed the positive staff and more than ¾ of youth interviewed thought the Bay Positive were “very successful” in helping them “feel like there are other people who care about me”. Similarly the Walden House Young Adult HIV Project (Hymel et al., 1998) found that the seven youth involved in their program evaluation had positive changes in their self-rated “overall well-being”. Using focus groups and a qualitative methodology, Rosenfeld et al
(2000) reported on the perceptions of youth regarding the adolescent health services provided through the Boston HAPPENS Program. They found that young people believed that the program had a positive impact on the accessibility and availability of youth specific health service through continuity of care, flexible scheduling, and connecting youth to care through peer leaders. Young people involved in the evaluation of the Boston HAPPENS program voiced a preference for youth-oriented services in a variety of healthcare setting such as free drop-in clinics and community health centres and highlighted provider characteristics such as competence and caring. They preferred that mental health and substance use services be “offered but not asked directly” (Rosenfeld et al., 2000, p. 64). Outreach is a key program element for engaging and retaining youth in HIV-related services (Woods et al., 2003; Woods et al., 2000). In the HAPPENS program, 56% of young people received outreach services at first contact, indicating the importance of outreach to engage young people in programs and youth seen at outreach were 10 times as likely to access medical care through the program (Woods et al., 2003; Woods et al., 2000). They also found that additional outreach, case management and mental health services were needed to retain youth (Woods et al., 2003).

Clinical programs offering services such as support groups showed positive changes in adolescent health outcomes. For example, Lyon and colleagues (2003) used a 12-week program with 23 HIV-positive youth (15-22 years old) and family member “treatment buddies” and a mixed approach of family sessions and peer-based sessions and found that young participants reported better adherence to medication regimens. Another program targeting medication adherence (Ellis et al., 2006) using Multisystemic Therapy for children/
adolescents and families living with perinatally-acquired HIV found that, although caregiver-reported child adherence did not change, HIV viral loads decreased significantly.

Some of the reports described the availability or utilization of services rather than using effectiveness measures. Lin and colleagues (1998) for example, described the services provided in metropolitan Boston for HIV-positive, homeless, and at-risk youth by 22 agency representatives, showing a range of services and ancillary services. The most popular services provided were case management (offered by 77% of agencies), life-style programs (73%), family counseling (59%), and outpatient mental health services (55%). Most of the agencies also provided ancillary services such as transportation vouchers, peer counseling, and medical screening (HIV, tuberculosis). “Lack of funding” was the most common barrier to increasing services for the youth. Harris et al (2003) showed that HIV-positive and at-risk participants had significantly longer retention times if they received outreach contacts, case management or more mental health counseling sessions. Some programs reported success in developing extensive referral services such as intensive case management, connecting HIV-positive and at-risk youth to medical services, social services, education, training, housing, and mental health services (Tenner et al., 1998b). Dilorenzo et al (1993) found that they could increase the number and diversity of referrals for HIV-positive and high-risk youth through implementing a targeted outreach program linking youth to HIV-prevention and service programs. Remafedi (2001) showed that the proportion of participants receiving case management services increased almost 20% after implementation of linking the statewide HIV public health surveillance system with case management services.
Overall, the results of these studies illustrate the high needs of the heterogeneous populations served by programs targeting HIV-positive adolescents and youth. The results suggest that some of the programs were effective at improving knowledge, health, and psychosocial outcomes and that some modalities of service delivery are perceived as better than others. Outreach, case management, and support were highlighted in many of the studies as key programmatic elements. However, although we are able to draw some conclusions from the results presented in the various reports, the qualities and characteristic that make the programs more or less successful are still largely unknown. This poses great difficulties in applying the knowledge gained to other programs in other contexts.

**Characteristics of Programs**

Intervention strategies were primarily individually focused with elements such as education, counseling, and skill-building. Some of the programs used a combination of individual, group (e.g., support group), and systemic strategies (e.g., community and provider education) to effect change at multiple levels simultaneously. These include: Health Initiatives for Youth (Bourdon et al., 1998); the Adolescent AIDS Program (Dilorenzo et al., 1993); Youth HIV Testing and Counseling Site Project (Silver et al., 1998); the Boston HAPPENS Program (Harris et al., 2003; Woods et al., 2003); the Larkin Street Youth Centre (Kennedy et al., 2000; Rotheram-Borus et al., 2001c); Walden House Young Adult HIV Program (Hymel et al., 1998); Bay Area Young Positives (Bettencourt et al., 1998); Children’s hospital of Los Angeles (Schneir et al., 1998); Indiana Youth Access Project (Wright et al., 1998); and Bridgeports’ Teen Outreach and Primary Services (Feudo et al., 1998).
The goals of the programs were variable but centered around connecting youth to services, promoting positive health and wellness and reducing risk for HIV-infected and at-risk young people (e.g., decreased mortality and morbidity, decreased risk behaviors and HIV transmission, and improved psychosocial well-being). Essentially, programs sought to provide various health and psychosocial services and to engage and retain young people in these services. The most common program formats included: case management services; volunteer counseling and HIV testing (VCT); primary care services; individual or group/family psychosocial support (e.g., support groups); peer-based services; outreach; education and empowerment/skill-building. Other services offered occasionally by programs included providing for basic needs, drop-in services, advocacy, alternative therapies, and recreation. Interventions occurred in a variety of settings including store front clinics, teaching hospitals/medical centers, residential care facility, clients’ homes, via telephone, community organizations and mobile van. All programs were based in urban areas. Populations of “youth” served varied from program to program but most commonly included young people aged 12-24 years.

Only 12 of the 27 programs explicitly stated a theoretical basis for their programs. This included Prochaska’s and DiClementi’s Stages of Change/Transtheoretical Model (Brown et al., 2000; Butler et al., 2003; Naar-King et al., 2006; Rogers et al., 2001; Schultz et al., 2001), the Social Action Model (Lightfoot et al., 2007; Rotheram-Borus 1998; 2001a; 2001d), the Theory of Reasoned Action (Brown et al., 2000; Butler et al., 2003; Schultz et al., 2001), Social Ecological Theory (Ellis et al., 2006); Family Systems Theory (Ellis et al., 2006; Weglarz & Boland, 2005), Social Marketing and Strategic Planning (Stanton et al.,
In terms of guidance for program design, implementation and evaluation, authors described several barriers and facilitators to program success. Barriers described included personal, social and structural factors. Facilitators or key elements to successful programs stated by the authors were related to service structure, delivery, and personnel. Examples of these are pooled and summarized in Table 4.3.

**Discussion**

The purpose of this review is not to critique any specific study or group of researchers but to address the difficulties that may arise when decision-makers look to the literature for their programming needs regarding HIV-positive youth. This review performs three distinct and useful tasks: it summarizes existing peer-reviewed literature regarding interventions involving youth in resource-rich countries post-HIV infection; extracts various program aspects such as program components, barriers and facilitating elements; and highlights gaps in the evidence base as a whole. By including a variety of study methodologies, this review attempted to minimize what Sandelowski (2007b) refers to as evidence typically “deleted” from research syntheses or a “bias towards exclusion”.

We can conclude from this review that the literature concerning successful programs/interventions for HIV-infected youth is very limited overall with only 46 reports

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Sandelowski (2007b) explains this exclusion by stating that: “the boundary work that defines systematic review is often so exclusionary as to eliminate most of what constitutes the larger arena in which that phenomenon is situated” (p. 243).
(27 unique programs) in 19 different journals identified in the peer-reviewed literature. This evidence is further constrained by the fact that more than half of the studies integrate HIV-positive with HIV at-risk youth. It overwhelmingly reflects only experiences of HIV-positive youth who access the American health care system. Barriers to programs for HIV-positive youth described (but not often ‘measured’) in this literature include various personal, social, and structural factors while factors that influence the success of a program are concerned with elements of program structure, delivery, and personnel.

Some articles that were excluded from the review (due to insufficient program description or lack of empirical program data regarding HIV-infected youth) provided additional insights into successful program design across studies. These studies furthered the discussion of necessary components of youth program implementation in terms of system changes such as capacity-building and service integration/collaboration (Botwinick et al., 2003), evaluation designs that include formative evaluation and a mix of qualitative and quantitative methods (Bell at al., 2003a), addressing organizational and staff communication issues (Meredith et al., 1998), early identification and essential case management (Woods et al., 2002b), and prevention, outreach and treatment models (Johnson et al., 2003b).

In terms of creating applied knowledge, this review found that studies need to be more comprehensive in terms of adequately describing program components and evaluating which elements are most relevant to its success. Elements that have been reported as key to successful programs with other young target populations, such as being theory-based (Kim et al., 1997), developmentally-appropriate (Pedlow & Carey, 2004), having buy-in from
community and administration (McKay, 2000), were poorly described or absent from many of the individual evaluations. Very few reports specified a particular framework for evaluation, the exceptions being the Empowerment Youth Evaluation (EYE) of the HIFY program (Bourbon et al., 1998), the cross-program SPNS evaluation (Huba & Melchoir, 1998), and the interventions trials related to TLC and CLEAR (Rotheram-Borus, 1998, 2001a, 2001d, 2004). Unfortunately, the information provided in the majority of the reports also did little to connect empirical evaluation outcomes to specific program elements, thereby making it difficult to ascertain the core elements of success. Barriers and facilitators were often stated but rarely linked to the specific outcomes being measured in the various articles. The synthesis and comparability of the reports was further challenged by several factors: the description of programs and their evaluations did not follow a standard format (e.g., “program description”, “evaluation methods”, “lessons learned”); elements of programs were not identified in sufficient detail; programs rarely described the same content or objectives; when programs were being described and evaluated, the distinction between the overarching organization elements and those of the programs being evaluated was often difficult to ascertain; and finally, the reports did not necessarily clearly capture characteristics or “core elements” (Ingram et al., 2008; Kelly et al., 2000) of program success.

What of the decision-makers trying to support effective policies and programs? Similar to researchers such as Stanton (1996) who have set forth criteria for evaluating intervention design, this review recommends that the following questions be addressed within articles to improve the ability to synthesize, assess, and compare studies to inform
policy and health promoting programs. Journal editors may also need to consider alternate authorship guidelines and word limits for these types of intervention and program studies.

- Is there a clear description of the scope of the program being evaluated in this study and how it fits into the broader organizational and community context and history?
- Does a clear distinction need to be made between populations, components and staff who are generally involved in the programs and those that are specifically involved in an evaluation process?
- Is the duration of the study/evaluation distinct or the same as the duration of the program itself?
- Is the program evaluation based on a specific evaluation framework?
- Are the study/evaluation methodology and its limitations adequately described?
- If full descriptions of methods or programs are not possible in the article, are references provided so that the reader can easily access this information from other articles or public sources?
- Are the characteristics of the participants and relevant sub-populations being served by the program described and potential differences noted?
- Are characteristics such as profession, training, and demographics of program staff and of “peers” provided?
- Are characteristics of the program itself clearly described including setting, objectives, content, activities, and funding?
- Have design and process elements as well as outcomes been described and evaluated?
• Do the lessons learned reflect study outcomes or is another source of knowledge production clearly articulated (e.g., the experiences and/or opinions of the authors)?

• What is not included in the study (e.g., what positive or negative outcomes may be important to program success but have not been explored?)

• Have authors clearly articulated the implications of the research/evaluation for programming and policy?

There are several limitations to this review. Reviews using standards health-related databases often do not readily access a broad range of qualitative studies on a given health topic (Dixon-Woods, 2001). However, the review was undertaken with the express purpose of finding peer-reviewed literature that is readily available and therefore did not attempt extraordinary measures such as searching grey literature, websites, or contacting individual authors for additional information. Some relevant articles may have been missed even though multiple search strategies were used. Program barriers and facilitating factors extracted were located in various sections of the studies and primarily reflected the expert opinions of the authors rather than a synthesis of study results per se. Finally, this review did not include broader public health programs or structural interventions (e.g., needle exchange programs, poverty alleviation strategies, laws prohibiting discrimination, etc) that HIV-positive youth may access and benefit from but are not HIV or youth-specific. Finding ways to link structural interventions to individual and community outcomes for youth would permit a more holistic examination of factors that extend beyond individual behaviors.
To date, model interventions have primarily targeted adult populations or uninfected youth. Lyles and colleagues (2007) recently published a review by the American Center for Disease Control and HIV/AIDS Prevention Research Synthesis (PRS) Team. This study evaluated HIV/AIDS behavioral interventions and identified 18 interventions that met the US CDC’s “Best Evidence” criteria. However, among these only three were specifically identified as targeting “at-risk youth” (DiClementi et al., 2004; Rotheram-Borus et al., 2004; Stanton et al., 2004; Wu et al., 2003) and only one of these targeted youth already HIV-infected (Rotheram-Borus et al., 2004). This type of intervention synthesis is a key source of information for program planners and interventionists yet is somewhat limited by its narrow definition of “evidence”. Lyles et al. (2007) acknowledges that some of the hardest hit populations lack representation in “best evidence” interventions and that these do not necessarily transfer to other populations and different settings. Advocates of evidence-informed decision-making need to encourage a proliferation of multiple evidentiary sources, including process evaluations and qualitative methodologies that provide contextual information about programs and allow the examination of difference between and within populations as well as questions not well suited to quantitative research designs. Likewise, support for more demonstration projects such as those funded by SPNS is essential for the development of successful HIV care models.

This review suggests that researchers move one step past the question “do the programs work?” to “what makes the programs work and for whom?” and that this be supported by specific evidence, including evidence examining process and contextual elements. Stanton et al (1996) state that it is important that authors begin to elucidate
decision-making regarding intervention design and that there exists a need for intervention frameworks or practical guidelines. Authors of intervention studies and program evaluations need to clearly articulate which program elements have been chosen for evaluation and how these are related to program success, as well as providing clear definitions of what constitutes ‘success’. This review echoes the call of other authors for the identification of “core elements” (Ingram et al., 2008; Kelly et al., 2000) that contribute to the success of HIV youth programs and factors affecting program transferability in different settings (Bell et al., 2007). The difficulty of synthesizing the literature for this review was not because of the differences between qualitative and quantitative evidence, but rather the need for multi-method comprehensive program evaluations providing rich program and contextual descriptions. These would enable decision makers to gain insight and hopefully make appropriate decisions to support effective health promoting programs with marginalized populations such as young people living with HIV.
Table 4.1: HIV programs targeting HIV-positive youth: Inclusion/exclusion selection criteria for review

<table>
<thead>
<tr>
<th>Criterion</th>
<th>Description</th>
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<tbody>
<tr>
<td>Article Purpose</td>
<td>Articles were eligible if they involved an intervention, program, or service targeting HIV-infected youth.</td>
</tr>
<tr>
<td>Design</td>
<td>Eligible articles included a description of an intervention, program or service specifically targeting HIV-infected youth. Various study designs were acceptable.</td>
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<tr>
<td>Population</td>
<td>Articles were eligible if their samples were derived from resource-rich countries such as the United States, Canada, Western Europe, and Australia. Studies were eligible if the programs they described included samples of HIV-infected youth with a proportion within the 13-25 year age range. Integrated populations of HIV-infected and at-risk young people were accepted as long as the inclusion of HIV-infected participants was explicit.</td>
</tr>
<tr>
<td>Outcomes</td>
<td>Articles were eligible if the elements of the intervention, program, or service were described in sufficient detail and if some empirical assessment/evaluation data was reported.</td>
</tr>
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</table>
### Table 4.2: Key characteristics of articles meeting inclusion criteria for review of programs for HIV-positive youth

<table>
<thead>
<tr>
<th>Program Names</th>
<th>First Author</th>
<th>Article Name</th>
<th>Year</th>
<th>Journal</th>
<th>Study Objective</th>
<th>Study Design</th>
<th>Study Population</th>
<th>Program target population</th>
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<tbody>
<tr>
<td>Adolescent AIDS Program (AAP) at the Montefiore Medical Center (Risk Evaluation Program)</td>
<td>Futterman, D</td>
<td>Human Immunodeficiency virus-infected Adolescents: The First 50 Patients in a New York City Program</td>
<td>1993</td>
<td>Pediatrics</td>
<td>To describe the Adolescent AIDS Program at the Montefiore Medical Center</td>
<td>Prospective Study consisting of a structured interview (cohort entering Adolescent AIDS Program)</td>
<td>n=93 total, n=50 HIV+</td>
<td>HIV+/at risk Adolescents age 13 to 21</td>
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<tr>
<td>Adolescent AIDS Program at the Montefiore Medical Center (AAP)</td>
<td>DiLorenzo, T</td>
<td>The evaluation of targeted outreach in an adolescent HIV/AIDS Program</td>
<td>1993</td>
<td>Journal of Adolescent Health</td>
<td>To describe a program establishing effective links between prevention and service programs for at-risk youth</td>
<td>Program model description</td>
<td>n=27 youth agencies targeted for outreach (identified 45 HIV+ youth through program)</td>
<td>HIV+/at risk youth 12-21 years old</td>
</tr>
<tr>
<td>Adolescent Women and Children Programs (AWAC). Includes 5 SPNS-funded programs: CHRRPY, SafeSpace, Wholelife, TOP-UM, DAYAM</td>
<td>Bell, DN</td>
<td>Case Findings for HIV-Positive youth: A special type of hidden population</td>
<td>2003</td>
<td>Journal of Adolescent Health</td>
<td>To describe the HIV case finding strategies (for VCT) used by the SPNS Adolescent HIV Outreach and Treatment programs, the populations of HIV-positive youth they were able to reach, and the populations of HIV-positive youth they were able to identify</td>
<td>Description of case finding strategies of 5 SPNS programs</td>
<td>n=2654 tested, 21 new HIV+ (CHRRPY), n=1507 tested, 35 new HIV+ (DAYAM), n=52 tested, new 3 HIV+ (SafeSpace), 267 tested, HIV+? (TOP-UM), 0 tested, 21 HIV+ (Whole Life)</td>
<td>HIV+/HIV- &amp; untested youth aged 12-24</td>
</tr>
<tr>
<td>Program Names</td>
<td>First Author</td>
<td>Article Name</td>
<td>Year</td>
<td>Journal</td>
<td>Study Objective</td>
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<tr>
<td>AWAC, DAYAM, University of Medicine</td>
<td>Johnson, RL</td>
<td>The Utilization of Treatment and Case Management Services by HIV-Infected Youth</td>
<td>2003</td>
<td>Journal of Adolescent Health</td>
<td>Describe the essential components for effective and comprehensive HIV care and youth who have tested positive and have been linked to HIV treatment; and present profiles of HIV+ participants in the 5 AWAC programs</td>
<td>Description of Youth, Service needs, Service utilization, and barriers confronted in AWAC programs</td>
<td>n=107 HIV+ youth</td>
<td>HIV+ and enrolled into treatment programs (85% over 18 years old), 15 to 25 years old</td>
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<td>Youth and Adolescent Medicine's</td>
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<tr>
<td>Treatment and Risk Reduction for Teens (START)</td>
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<td>Transitioning Youths into care: Linking Identified HIV-Infected Youth at Outreach Sites in the Community to Hospital-based Clinics and or Community-based Health Centers</td>
<td>2003</td>
<td>Journal of Adolescent Health</td>
<td>To describe and analyze the process of transitioning HIV-infected youth from point of HIV diagnosis into HIV treatment</td>
<td>Survey at baseline of needs and barriers of AWAC participants</td>
<td>n=107 HIV+ youth 15 to 24 years</td>
<td>HIV+ youth from 5 SPNS programs</td>
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<tr>
<td>AWAC: CHRRPY, DAYAM, SafeSpace, TOP-UM, WholeLife</td>
<td>Martinez, J</td>
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<tr>
<td>Bay Area Young Positives</td>
<td>Bettencourt, T</td>
<td>Bay Area Young Positives</td>
<td>1998</td>
<td>Journal of Adolescent Health</td>
<td>To describe a peer-run, peer-based organizational model for HIV-positive youth</td>
<td>Program model Description</td>
<td>n=181 HIV+</td>
<td>HIV+ young people 26 and under</td>
</tr>
<tr>
<td>Program Names</td>
<td>First Author</td>
<td>Article Name</td>
<td>Year</td>
<td>Journal</td>
<td>Study Objective</td>
<td>Study Design</td>
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<td>Program target population</td>
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<tr>
<td>Boston HAPPENS</td>
<td>Woods, ER</td>
<td>Initiation of services in the Boston HAPPENS Program: Human Immunodeficiency</td>
<td>2002</td>
<td>AIDS Patient Care and STDs</td>
<td>To evaluate the factors associated with initiation of services in the Boston HAPPENS Program, which is a collaborative network of care consisting of multiservice outreach agencies, community health centers and hospitals, for HIV-positive and hard to reach youth 12-24</td>
<td>Cohort longitudinal study</td>
<td>n= 2116 total, n=38 HIV+</td>
<td>HIV+/at-risk youth 12-24 years</td>
</tr>
<tr>
<td>Boston HAPPENS (HIV Adolescent Provider and Peer Education Network for Services): Children's hospital, Boston Medical Center, New England Medical Centre, Dimock Community Health Center, Bridge Over Troubled Waters, Justice Resource Institute, Roxbury Comprehensive Community Health Centre, and Martha Eliot Health Centre</td>
<td>Rosenfeld, SL</td>
<td>Youth Perceptions of Comprehensive Adolescent Health Services Through the Boston HAPPENS Program</td>
<td>2000</td>
<td>Journal of Pediatric Health Care</td>
<td>To evaluate youth perceptions about the Boston HAPPENS Program</td>
<td>Client centered qualitative program evaluation</td>
<td>n=18 youth served by the network were involved in the evaluation, n=3 HIV+</td>
<td>HIV+/at risk and homeless youth ages 12-24</td>
</tr>
<tr>
<td>Program Names</td>
<td>First Author</td>
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<td>The Boston Happens Program: needs and use of services by HIV+ compared with at-risk youth, including gender differences</td>
<td>2000</td>
<td>Evaluation and Program planning</td>
<td>To assess the utilization of health services by clients of the Boston HAPPENS program</td>
<td>Observational cohort</td>
<td>n=1044 total, n=26 HIV+</td>
<td>HIV+/HIV- &amp; untested youth aged 12-24</td>
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<td>Program Names</td>
<td>First Author</td>
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<tr>
<td>Boston HAPPENS (HIV Adolescent Provider and Peer Education Network for Services)</td>
<td>Woods, ER</td>
<td>Boston Happens Program: HIV-positive, Homeless, and At-risk Youth Can Access Care through Youth-Oriented HIV Services</td>
<td>2003</td>
<td>Seminars in Pediatric Infectious Diseases</td>
<td>To describe the epidemiology of HIV/AIDS in adolescents, the Boston HAPPENS program and an overview of its evaluation and key findings</td>
<td>Program model description and mixed method evaluation (observational cohort)</td>
<td>n=2116 total, n=54 HIV+</td>
<td>HIV+/HIV- &amp; untested youth aged 12-24</td>
</tr>
<tr>
<td></td>
<td>Lin, YG.</td>
<td>Evaluation of a Linked Service Model of Care for HIV-Positive, Homeless, and at-risk Youths</td>
<td>1998</td>
<td>AIDS Patient Care and STDs</td>
<td>To evaluate an agency's type and availability of services for HIV-positive and at-risk adolescents, and to assess opinions concerning healthcare referral patterns</td>
<td>Survey of 22 agencies HIV services</td>
<td>n= 22 ancillary youth service representatives</td>
<td>47 HIV+ youth 12-24 years in Boston HAPPENS 9 core programs</td>
</tr>
<tr>
<td>Program Names</td>
<td>First Author</td>
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<tr>
<td>Boston HIV Adolescent Provider and Peer Education Network (Boston HAPPENS)</td>
<td>Harris, SK</td>
<td>Outreach, mental health, and case management services: can they help to retain HIV-positive and at-risk youth and young adults in care?</td>
<td>2003</td>
<td>Maternal and Child Health Journal</td>
<td>To assess the impact of outreach, mental health, and case management services on retention in primary care of HIV+ and at risk youth and young adult clients of the Boston HAPPENS Program, a comprehensive adolescent HIV prevention and care network of agencies</td>
<td>Prospective cohort study</td>
<td>n=1426, n=37 HIV+</td>
<td>HIV+/at-risk youth 12-24 years</td>
</tr>
<tr>
<td>Bridgeport's Teen Outreach and Primary Services (TOPS) Projects; Part of the Greater Bridgeport Adolescent Pregnancy Program</td>
<td>Feudo, R</td>
<td>Bridgeport's Teen Outreach and Primary Services (TOPS) Project</td>
<td>1998</td>
<td>Journal of Adolescent Health</td>
<td>To describe a model for raising community awareness about Adolescent HIV risk (including program model, organization, and client flow chart)</td>
<td>Program model Description (TOPS)</td>
<td>n=2173, n=17 HIV+</td>
<td>HIV+/at-risk inner-city minority youth aged 15-24</td>
</tr>
<tr>
<td>Children's Hospital Los Angeles</td>
<td>Schneir, A</td>
<td>Children's Hospital Los Angeles. A Model of Integrated Care for HIV-Positive and Very High Risk Youth</td>
<td>1998</td>
<td>Journal of Adolescent Health</td>
<td>To describe program model and evaluation results</td>
<td>Service model description and mixed methods evaluation</td>
<td>n=8400 youth served by outreach; clinical services to 296 young men (16.6% or 49 HIV+), 352 young women (9.1% or 32), total= 648 HIV- and 81 HIV+</td>
<td>HIV+/at risk Adolescents</td>
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<td>Program Names</td>
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<tr>
<td>Children's Hospital of Michigan</td>
<td>Ellis, DA</td>
<td>Use of Multisystemic therapy to Improve Antiretroviral Adherence and Health Outcomes in HIV-Infected Pediatric Patients: Evaluation of a Pilot Program</td>
<td>2006</td>
<td>AIDS Patient Care and STDs</td>
<td>To evaluate a clinical program that used multisystemic therapy (MST) to improve regimen adherence and health outcomes among children with perinatally-acquired HIV who exhibit high viral loads in the absence of viral resistance</td>
<td>Evaluation of clinical MST program by retrospective chart review</td>
<td>19 children, Average age 11.3 (SD 3.8, range 20m-16yrs)</td>
<td>HIV+ children and their families identified as having severe adherence problems. HAART therapy for at least 6 months, 16 years and younger</td>
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<tr>
<td>Clean living, Empowerment and Results (CLEAR)</td>
<td>Lightfoot, M</td>
<td>Who benefited from an efficacious intervention for youth living with HIV: a moderator analysis</td>
<td>2007</td>
<td>AIDS Behavior</td>
<td>To examine the characteristics of the young people living with HIV that influences an intervention's success</td>
<td>Randomized controlled intervention trial</td>
<td>n=175 HIV+</td>
<td>HIV+ youth 16-29 years</td>
</tr>
<tr>
<td>Francois-Xavier Bagnoud Center</td>
<td>Weglarz, M</td>
<td>Family-centered nursing care of the perinatally-infected mother and child living with HIV infection</td>
<td>2005</td>
<td>JSPN</td>
<td>To describe the care of the perinatally HIV-infected woman and her child with HIV infection</td>
<td>Case study</td>
<td>n=1 HIV+ young mother</td>
<td>HIV+ mother-child dyads with perinatal infection</td>
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<tr>
<td>Program Names</td>
<td>First Author</td>
<td>Article Name</td>
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<td>HBIEP</td>
<td>Butler, R</td>
<td>Promoting safer sex among HIV-positive youth with haemophilia: theory, intervention, and outcome</td>
<td>2003</td>
<td>Haemophilia</td>
<td>To develop and evaluate theory-based interventions designed to change sexual behavior and promote safer sex practices of HIV seropositive young men with haemophilia to prevent HIV transmission</td>
<td>Single arm, multi-site longitudinal observational study</td>
<td>n=104 HIV+</td>
<td>HIV+ adolescents males with haemophilia, 13-24 years</td>
</tr>
<tr>
<td>HBIEP</td>
<td>Schultz, R</td>
<td>Developing theory-based risk-reduction interventions for HIV-positive young people with haemophilia</td>
<td>2001</td>
<td>Haemophilia</td>
<td>To describe the process used to develop the HBIEP interventions</td>
<td>Mixed-methods developmental study</td>
<td>n=356 HIV+ youth</td>
<td>HIV+ adolescents males with haemophilia, 13-24 years</td>
</tr>
<tr>
<td>HBIEP (Hemophilia Behavioral Intervention Evaluation Project)</td>
<td>Brown, LK</td>
<td>Sexual behavior change among human immunodeficiency virus-infected adolescents with hemophilia</td>
<td>2000</td>
<td>Pediatrics</td>
<td>To determine the effectiveness of a behavioral intervention program in promoting safer sexual behaviors among adolescent young/adult males with hemophilia and HIV infection</td>
<td>Single-arm observational study</td>
<td>n=111 HIV+</td>
<td>HIV+ adolescents males with haemophilia, 12-24 years</td>
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<td>Program Names</td>
<td>First Author</td>
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<td>Healthy Choices</td>
<td>Naar-King, S</td>
<td>Healthy Choices: motivational enhancement therapy for health risk behaviors in HIV-positive youth</td>
<td>2006</td>
<td>AIDS Education and Prevention</td>
<td>To determine whether HIV-positive youth could be recruited and retained in a motivational intervention study targeting health risk behaviors and to determine if the motivational intervention would improve these behaviors and health outcomes</td>
<td>Randomized controlled intervention trial</td>
<td>n= 51 HIV+ (25 intervention, 26 control)</td>
<td>HIV+ youth 16-25 years</td>
</tr>
<tr>
<td>HIFY: Health Initiatives for Youth: 3 interconnecting programs: Training and Resource Center, Project AHEAD, Youth Health Initiative</td>
<td>Bourdon, B</td>
<td>Health Initiatives for Youth</td>
<td>1998</td>
<td>Journal of Adolescent Health</td>
<td>To describe program model and evaluation results (including program model, organizational description, and EYE evaluation model)</td>
<td>Program HIFY model Description, YHI Evaluation</td>
<td>n=136 male (33.1%/45ppl HIV+), n=164 female (12.2%/20ppl HIV+). Total 300 (Approx 65 HIV+)</td>
<td>HIV+/at risk young people age 13-25 yrs</td>
</tr>
<tr>
<td>Indiana Youth Access Project</td>
<td>Wright, ER</td>
<td>Indiana Youth Access Project: a model for responding to the HIV risk behaviors of gay, lesbian, and bisexual youth in the Heartland</td>
<td>1998</td>
<td>Journal of Adolescent Health</td>
<td>To describe the IAP service model and evaluation</td>
<td>Program model description and evaluation</td>
<td>n=418, n=9 HIV+</td>
<td>HIV+/at-risk gay/lesbian/bisexual youth under 25</td>
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<tr>
<td>Program Names</td>
<td>First Author</td>
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<tr>
<td>Larkin Street Youth Center</td>
<td>Stanton, A</td>
<td>Developing services for substance-abusing HIV-positive youth with mental health disorders</td>
<td>2000</td>
<td>The Journal of Behavioral Health Services &amp; Research</td>
<td>To describe how the need for the new set of housing services was established; how the support of policy leaders, community activists, and funders was mobilized; and how barriers that could have prevented the program's implementation were overcome</td>
<td>Qualitative case study</td>
<td>n=16 staff members, community leaders, administrative leaders, donors, etc</td>
<td>HIV+ youth</td>
</tr>
<tr>
<td>Larkin Street Youth Centre Residential Program</td>
<td>Rotheram-Borus, MJ</td>
<td>Health and risk behaviors over time among youth living with HIV</td>
<td>2001</td>
<td>Journal of Adolescence</td>
<td>To document health and risk behaviors over time among multiply diagnosed youth living with HIV who are receiving comprehensive residential care</td>
<td>Cohort longitudinal study</td>
<td>n=25 HIV+</td>
<td>HIV+ disabled youth living in residential care program 19-24 years old</td>
</tr>
<tr>
<td>Larking Street Youth Centre</td>
<td>Kennedy, M</td>
<td>A continuum of care model for adolescents living with HIV: Larkin Street Youth Center</td>
<td>2000</td>
<td>Drugs and Society</td>
<td>To describe the multiple levels of needs among adolescents living with HIV and a model system of care that uses a rank ordered set of needs for these youth</td>
<td>Describes Program and Qualitative Case Studies</td>
<td>n=2000, n=90 HIV+ (LSYC), n=7 HIV+ (case studies)</td>
<td>HIV+ at-risk homeless and runaway youth 18-24</td>
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<tr>
<td>Program Names</td>
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<tr>
<td>Not stated</td>
<td>Funck-Brentano, I</td>
<td>Evaluation of a peer support group therapy for HIV-infected adolescents</td>
<td>2005</td>
<td>AIDS</td>
<td>To assess the effects of a peer support group therapy on HIV-infected adolescents</td>
<td>Prospective cohort study</td>
<td>n = 30 HIV+ (3 groups of 10)</td>
<td>HIV+ perinatally infected adolescents 12-18 years</td>
</tr>
<tr>
<td>Not stated</td>
<td>Lyon, M</td>
<td>A family group approach to increasing adherence to therapy in HIV-infected youths: results of a pilot project</td>
<td>2003</td>
<td>AIDS Patient Care and STDs</td>
<td>To describe the development of a novel, pilot program in which a combined family group and peer approach were used to increase adherence to antiretroviral therapy in HIV-infected youths</td>
<td>Intervention study</td>
<td>n = 23 HIV+ youth</td>
<td>HIV+ youth 15-22 years and their &quot;treatment buddies&quot;</td>
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<tr>
<td>Not stated</td>
<td>Rotheram-Borus, MJ</td>
<td>Secondary prevention for youth living with HIV</td>
<td>1998</td>
<td>AIDS Care</td>
<td>To summarize formative research and describe an intervention aimed at implementing and maintaining: healthy daily routines, health management and medical adherence; safer sexual behavior and abstinence from substance use; and a high quality of life</td>
<td>Ethnographic study and intervention piloting</td>
<td>n = 85 HIV+ youth</td>
<td>HIV+ youth</td>
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<tr>
<td>Program Names</td>
<td>First Author</td>
<td>Article Name</td>
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<td>Not stated</td>
<td>Rotheram-Borus, MJ</td>
<td>Improving the quality of life among young people living with HIV</td>
<td>2001</td>
<td>Evaluation and Program planning</td>
<td>To examine the results from an intervention module, Being Together, aimed at improving quality of life in young people living with HIV</td>
<td>Controlled Cohort Intervention Study</td>
<td>n= 266 HIV+ (182 intervention, 84 control), 104 participated in 3rd module</td>
<td>HIV+ youth 14-23 years old</td>
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<tr>
<td>Not stated</td>
<td>Rotheram-Borus, MJ</td>
<td>Prevention for substance-using HIV-positive young people: Telephone and in-person delivery</td>
<td>2004</td>
<td>JAIDS</td>
<td>To examine the efficacy of an intervention to reduce transmission acts and compare telephone and in-person modalities</td>
<td>Randomized controlled intervention trial</td>
<td>n=175 HIV+</td>
<td>HIV+ youths 16 to 29 years old, focused on drug using youth</td>
</tr>
<tr>
<td>Not stated</td>
<td>Song, J</td>
<td>Predictors of intervention adherence and young people living with HIV</td>
<td>2006</td>
<td>American Journal of Health Behavior</td>
<td>To identify the environmental, personal, and situational factors that influence attendance among young people living with HIV</td>
<td>Randomized controlled intervention trial</td>
<td>n=310 HIV+ Youth</td>
<td>HIV+ youth in 3 epicenters</td>
</tr>
<tr>
<td>SPNS Programs: Children's Hospital of Boston, Children's Hospital of LA, Health Initiatives for Youth, BAY Area Young Positives, University of Minnesota, Minnesota Department of Health, YouthCare, State of Indiana, University of Alabama, Walden house</td>
<td>Huba, GJ</td>
<td>A Model for Adolescent-Targeted HIV/AIDS Services</td>
<td>1998</td>
<td>Journal of Adolescent Health</td>
<td>To describe a model of service for youth living with HIV and youth at high risk for HIV, based on the lessons learned from a set of innovative service projects funded by HRSA-SPNS Program</td>
<td>Description of 10 program models</td>
<td>n=4437 across projects using outpatient service interventions, 517 HIV+, 3920 youth at-risk</td>
<td>HIV+/at risk youth aged 12-24</td>
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<tr>
<td>Program Names</td>
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<td>SPNS Programs: Children's Hospital of Boston, University of North Carolina,</td>
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<td>Service Use Patterns of Youth with, and at High Risk for, HIV: a Care Typology</td>
<td></td>
<td>AIDS Patient Care and STDs</td>
<td>To use confirmatory structural equation models to develop and test a theoretical</td>
<td>Descriptive synthesis (using typologies and structural equation modeling)</td>
<td>n=4679 Youth received services (2166 men &amp; 2508 women); 578 HIV+ (423 men &amp; 155 women)</td>
<td>HIV+/at risk Youth</td>
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<tr>
<td>Chapel Hill, Greater Bridgeport Adolescent Pregnancy Project, Indiana University</td>
<td>Huba, GJ</td>
<td></td>
<td>2000</td>
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<td>model for understanding the service utilization history of 4679 youth who received</td>
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<td>Purdue, Children's Hospital of LA, Health Initiatives for Youth, BAY Area Young</td>
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<td>services from 10 national HIV/AIDS demonstration models of youth-appropriate and</td>
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<tr>
<td>Positives, University of Minnesota Youth and AIDS Projects, Health Initiatives</td>
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<td>youth-attractive services (SPNS)</td>
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<td>for Youth, YouthCare, State of Indiana, University of Alabama, Walden house</td>
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<tr>
<td>Teenage Access Project (TAP), MIRROR (My individual responsibility reduces our</td>
<td></td>
<td>The University of Alabama Teenage Access Project</td>
<td>1998</td>
<td>Journal of Adolescent Health</td>
<td>To describe the TAP program model for prevention, referrals, and linkages to</td>
<td>Program model description; pre and post-test intervention evaluation</td>
<td>n= 403 youth (HIV+?)</td>
<td>HIV+/at risk Adolescents age 10 to 21</td>
</tr>
<tr>
<td>risk), Adolescent Testing Center</td>
<td>Sturdevant, MS</td>
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<td></td>
<td></td>
<td>testing for high-risk young women</td>
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<tr>
<td>Program Names</td>
<td>First Author</td>
<td>Article Name</td>
<td>Year</td>
<td>Journal</td>
<td>Study Objective</td>
<td>Study Design</td>
<td>Study Population</td>
<td>Program target population</td>
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<tr>
<td>Teens Linked to Care (TLC)</td>
<td>Lee, M</td>
<td>Cost-effectiveness of a behavioral intervention for seropositive youth</td>
<td>2005</td>
<td>AIDS Education and Prevention</td>
<td>To examine the cost effectiveness of an intervention to reduce transmission among HIV-positive youth</td>
<td>Case controlled program evaluation</td>
<td>n=310 (208 intervention, 102 control)</td>
<td>HIV+ youth (22.2 mean age)</td>
</tr>
<tr>
<td>TLC</td>
<td>Rotheram-Borus, MJ</td>
<td>Efficacy of a Preventive Intervention for Youths Living with HIV</td>
<td>2001</td>
<td>American Journal of Public Health</td>
<td>HIV transmission behaviors and health practices of HIV-infected youths were examined over a period of 15 months after they received a preventive intervention</td>
<td>Controlled Cohort Intervention Study</td>
<td>n=310 HIV+ Youth</td>
<td>HIV+ Youth age 13-24</td>
</tr>
<tr>
<td>TREAT: Adolescent Medicine HIV/AIDS Research Network (AMHARN), REACH</td>
<td>Rogers, AS</td>
<td>The TREAT (Therapeutic Regimens Enhancing Adherence in Teens) Program: Theory and Preliminary Results</td>
<td>2001</td>
<td>Journal of Adolescent Health</td>
<td>To produce and implement a theory-based clinical intervention to promote adherence to antiretroviral therapy (HAART) among HIV infected youth</td>
<td>Quasi-experimental design (On-HAART, On Non-HAART, No Therapy)</td>
<td>n= 65 HIV+ youth REACH clients accepted the program, n=18 received full program</td>
<td>HIV+ youth enrolled in REACH program</td>
</tr>
<tr>
<td>Program Names</td>
<td>First Author</td>
<td>Article Name</td>
<td>Year</td>
<td>Journal</td>
<td>Study Objective</td>
<td>Study Design</td>
<td>Study Population</td>
<td>Program target population</td>
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<tr>
<td>Walden House Young Adult HIV Project (YAH)</td>
<td>Hymel, MS</td>
<td>The Walden House Young Adult HIV Project</td>
<td>1998</td>
<td>Journal of Adolescent Health</td>
<td>To describe the Walden House Young Adult HIV Project for meeting the needs of multi-diagnosed youth</td>
<td>Project Description</td>
<td>n=512 total, n=101 HIV+</td>
<td>HIV+/at risk youth; Multidiagnosed young people aged 13-25, substance abuse, mental health, HIV+ or high risk</td>
</tr>
<tr>
<td>Whole Life</td>
<td>Dodds, S</td>
<td>Retention, adherence, and compliance: Special needs of HIV-infected adolescent girls and young women</td>
<td>2003</td>
<td>Journal of adolescent health</td>
<td>To demonstrate that although all HIV-infected youth evidence complex factors that challenge retention in care and adherence to treatment, HIV infected females have additional issues that are gender-specific</td>
<td>Descriptive cohort study</td>
<td>n= 21 HIV+</td>
<td>HIV+ young women under 25</td>
</tr>
<tr>
<td>Program Names</td>
<td>First Author</td>
<td>Article Name</td>
<td>Year</td>
<td>Journal</td>
<td>Study Objective</td>
<td>Study Design</td>
<td>Study Population</td>
<td>Program target population</td>
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<tr>
<td>YAP</td>
<td>Remafedi, G</td>
<td>Linking HIV-Seropositive Youth with Health Care: Evaluation of an Intervention</td>
<td>2001</td>
<td>AIDS Patient Care and STDs</td>
<td>To assess the proportion of HIV-positive youth enrolled in case management services before and after an intervention (to link to case management)</td>
<td>Program evaluation; case controlled study</td>
<td>53 HIV+ youth aged 14-23 reported from the D.O.H from May 1992 to Nov 1998. 40 completed interviews, comparison group of 89 13-21 yr olds diagnosed with HIV from Oct 1985 to April 1992</td>
<td>HIV+ Youth (13 to 23 years old)</td>
</tr>
<tr>
<td>Youth and AIDS Projects (YAP) Adolescent Early Intervention Program</td>
<td>Remafedi, G</td>
<td>The University of Minnesota Youth and AIDS Projects' Adolescent Early Intervention Program</td>
<td>1998</td>
<td>Journal of Adolescent Health</td>
<td>To describe a model (project setting, conceptual framework, intervention methods, and ongoing evaluation) to link HIV-seropositive youth with care</td>
<td>Description of program model, needs assessment, evaluation</td>
<td>n=36 HIV+ youth aged 17-23 participated in evaluation</td>
<td>HIV+ Youth aged 13-22; reported by Minnesota Dep't of Health</td>
</tr>
<tr>
<td>Program Names</td>
<td>First Author</td>
<td>Article Name</td>
<td>Year</td>
<td>Journal</td>
<td>Study Objective</td>
<td>Study Design</td>
<td>Study Population</td>
<td>Program target population</td>
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<tr>
<td>Youth HIV Counseling and Test Site Project</td>
<td>Silver S</td>
<td>Direct Evaluation of Adolescent HIV Counseling and Testing Services</td>
<td>1998</td>
<td>AIDS Patient Care and STDs</td>
<td>To provide direct evaluation of services provided to youths by adolescents trained to address critical issues using fictional stories at actual sites advertising HIV/AIDS counseling and testing to teenagers</td>
<td>Cross-sectional survey of VCT sites</td>
<td>n= 25 VCT sites</td>
<td>All populations; there were youth on organizing committee and acting as evaluators to assess &quot;youth friendliness&quot; of sites</td>
</tr>
<tr>
<td>YouthCare, TOPS, Boston HAPPENS</td>
<td>Tenner, A</td>
<td>Shared Experiences: Three programs serving HIV+ Youths</td>
<td>1998</td>
<td>Child Welfare</td>
<td>To describe and compare three program serving HIV+ and at risk youth</td>
<td>Program model description</td>
<td>Youth: Total=4576; HIV+: BH=12; YC=30; TOPS=12</td>
<td>HIV+/at risk Adolescents 12 - 25 years</td>
</tr>
<tr>
<td>YouthCare; Adolescent Health Promotion Program (since 1988); Prevention, Intervention, and Education Program (PIE since 1992, SPNS funded)</td>
<td>Tenner, A</td>
<td>Seattle YouthCare's Prevention, Intervention, and Education Program</td>
<td>1998</td>
<td>Journal of Adolescent Health</td>
<td>To describe and evaluate Seattle's YouthCare Prevention, Intervention and Education Program</td>
<td>Program model description and mixed method evaluation</td>
<td>n=906 total, n=37 HIV+ in program and profiled; quantitative evaluation with 272 youth</td>
<td>HIV+/at risk Adolescents</td>
</tr>
</tbody>
</table>
Table 4.3: A summary of program barriers and program facilitators pooled from 46 publications describing interventions and programs including youth living with HIV

<table>
<thead>
<tr>
<th>Program Barriers</th>
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<tbody>
<tr>
<td><strong>Personal</strong></td>
</tr>
<tr>
<td>• lack of awareness among youth about services</td>
</tr>
<tr>
<td>• requirements of daily living</td>
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<tr>
<td>• psychological and developmental barriers (e.g., denial, fear, or a lack of future orientation)</td>
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<tr>
<td><strong>Social</strong></td>
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<tr>
<td>• stigma and community norms</td>
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<tr>
<td>• cost of services or lack of funding sources</td>
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<tr>
<td>• difficulties finding trusted and respectful relationships with adult providers</td>
</tr>
<tr>
<td>• cultural insensitivity/linguistic barriers</td>
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<tr>
<td><strong>Structural</strong></td>
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<tr>
<td>• transportation difficulties</td>
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<tr>
<td>• lack of adolescent-specific services</td>
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<tr>
<td>• laws and institutional policies governing adolescents’ consent and confidentiality</td>
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<th>Program Facilitators</th>
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<tr>
<td><strong>Service structure</strong></td>
</tr>
<tr>
<td>• one-stop shopping and multidisciplinary models of care</td>
</tr>
<tr>
<td>• consistency of approach and availability</td>
</tr>
<tr>
<td>• providing for basic needs and stability</td>
</tr>
<tr>
<td>• using a developmental framework</td>
</tr>
<tr>
<td>• treatments and clinic schedules that fit adolescent lifestyles and schedules</td>
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<tr>
<td>• comprehensive care environments including outreach, case management, and mental health services</td>
</tr>
<tr>
<td>• flexible collaborative networks of care</td>
</tr>
<tr>
<td>• adult and youth partnerships</td>
</tr>
<tr>
<td>• non-identifying HIV treatment sites</td>
</tr>
<tr>
<td>• administrative support</td>
</tr>
<tr>
<td><strong>Service delivery</strong></td>
</tr>
<tr>
<td>• extensive formative research</td>
</tr>
<tr>
<td>• youth involvement in program planning and as peers/staff</td>
</tr>
<tr>
<td>• family and partner involvement</td>
</tr>
<tr>
<td>• youth-oriented services tailored to the population</td>
</tr>
<tr>
<td>• focus on overall quality of life</td>
</tr>
<tr>
<td>• multiple modalities</td>
</tr>
<tr>
<td>• individualized programming were highlighted as important factors</td>
</tr>
<tr>
<td><strong>Service providers</strong></td>
</tr>
<tr>
<td>• designated staff members being familiar with unique developmental, medical, and psychosocial needs of adolescents</td>
</tr>
<tr>
<td>• staff characteristics such as being competent, relaxed, caring, understanding, and friendly</td>
</tr>
<tr>
<td>• staff who maintain confidentiality and communicating clearly and honestly</td>
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</table>
References


Introduction

Globally, almost half of new HIV infections happen in young people under 25 years old (UNAIDS, 2008). HIV-infected adolescents and youth have been identified largely as a ‘hidden population’, socially and economically marginalized, often street entrenched, and chronically underserved by traditional healthcare and social service models (Bell et al., 2003; Martinez et al., 2003; Tenner et al., 1998). Their health and well-being may be influenced by multiple factors including high rates of unstable housing (DeMatteo et al., 1999; Miller et al., 2002; Roy et al., 2003), school drop-out and unemployment (Ramefadi & Lauer, 1996), substance abuse (Roy et al., 2003; Miller et al., 2004), and mental health issues such as depression (Murphy et al., 2001). Higher levels of depression in this population have been associated with more unprotected sex and lower levels of social support and coping (Murphy et al., 2001). Unsafe sexual practices, re-infection, unintended pregnancy, and sexually transmitted infections are reported risks in populations of HIV-infected adolescents (Miller et al., 2004; Murphy et al., 2001; Belzer et al., 2001; Hein & Dell, 1995; Vermund et al., 2001).

HIV-infected young people in resource-rich countries are characterized by diversity, with the highest prevalence among young injection drug users and men who have sex with men (MSM) (Futterman, 2004; PHAC, 2007). Additionally, cohorts of perinatally-infected

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children are now transitioning into adolescence and young adulthood with the assistance of treatment and specialized HIV services (Futterman, 2004). Adolescents, while by no means forming a homogenous social or cultural group, share common developmental and health care needs that are distinct from those of children and adult populations, partly determined by cultural norms and values and marked by major life transitions.

Service providers are currently facing challenges associated with integrating these varied populations of HIV-infected young people. Researchers are calling for models to guide service delivery (Woods et al., 2002). Despite these demands, scant evidence exists to support the development and implementation of holistic interventions to care for and support HIV-infected adolescents. The objective of this study was to identify and prioritize core elements of post-infection programs for adolescents living with HIV in resource-rich settings.

Methods

Qualitative research is increasingly being used in health service program and policy research. Its methods are useful in generating theoretical and empirical knowledge about social processes, cultural knowledge, and people’s understandings of their everyday lives (Pope & Mays, 1999; Strauss & Corbin, 1998). As such, it is ideal for designing effective programs for communities through a systematic process of inquiry embedded within historical, political, social and cultural contexts. This study was part of a multi-step project to design a health promotion program model targeting HIV-infected adolescents, including those with perinatally-acquired HIV (Fielden et al., 2008). The research was approved by the Behavioural Ethical Review Board of the University of British Columbia (Appendix A).
The research methodology was guided by constructivist qualitative inquiry and employed individual, semi-structured interview techniques (Pope & Mays, 1999) to obtain rich and comparable data about key programming considerations from the perspective of ‘experts’. Potential participants were initially located through searching peer-reviewed and grey literature. They were selected purposively based on their experience as service providers and interventionists in the field of Adolescent HIV and via snowball sampling. Sampling ceased when saturation (Strauss & Corbin, 1998) was achieved and the final two interviews yielded no new themes.

Interviews were conducted by telephone and included open-ended questions to deepen understanding and allow space for rich description. Participants were asked to describe the programs with which they were historically or presently engaged, to reflect on the core elements for successful programs with HIV-infected adolescents, and to expand on barriers to programming such as HIV-related stigma (see interview scripts, Table 5.1). Interviews were conducted from May to August 2007 by the same bilingual investigator (first author), 13 in English and two in French. They ranged from approximately 20 minutes to approximately 1 hour 10 minutes in length, were audio-recorded digitally and transcribed verbatim. Salient passages from the French transcripts were translated into English by an independent francophone translator and checked for accuracy through back translation. Transcripts were entered into NVivo 7.0 (QSR International) qualitative software to facilitate coding, comparison, and overall data management.
The analysis of all the interviews included memoing (Miles & Huberman, 1994) about the evolution of coding categories and maintaining a reflexive journal to record questions, key concepts and other considerations arising during the analysis. Analysis initially used line-by-line coding of the transcripts to identify codes and to create a coding framework. Transcripts were subsequently coded through “chunking” the data (Miles & Huberman, 1994), and by coding for individual questions and text queries. The coding sought to decontextualize the data through identifying and grouping themes. Core elements emerged through interpretive comparative analysis and recontextualization, thereby capturing the most salient ideas expressed by participants through grouping them into overarching categories. Experts were invited to give responses based on Figure 5.1 to offer further information or opinions confirming or refuting the components of the model. Responses (n=2) were integrated into the final model. This practice is consistent with what is termed ‘hermeneutic cycles’ (Guba & Lincoln, 1989) to help in the co-construction of knowledge.

**Results**

**Participant Characteristics**

Out of the 34 experts who received an invitation, 20 responded and fifteen agreed to participate. Select characteristics of participants are represented in Table 5.2. The group was disproportionately female and almost half (seven) of the participants were from the US followed by Canada (four), the UK (two) and Australia (two). All participants were professionally trained and educated with the majority holding either an MD or a PhD in a health-related field. Most were directors of adolescent HIV services and/or appointed university faculty members. Three exceptions to this were: an International HIV program consultant with health-related professional degrees completing a PhD; an administrative and
evaluation manager for an adolescent HIV program holding a Masters of Public Health; and a senior social worker at a specialized family HIV clinic. Cumulatively the participants possessed a wealth of experience with over half having 15 years or more of experience in the fields of HIV and Adolescent Health. Median number of years of experience with HIV and adolescents was 15 years (range: 4-26) and 18 years (range: 5-35) respectively.

Core Program Elements

Ten overarching categories emerged from thematic analysis representing the synthesis of a group of experiences, and ideas expressed by participants. Figure 5.1 identifies subcategories that provide examples of the various ways in which participants reflected on the realities of providing services to adolescents infected with HIV. These are further expanded upon and illustrated through the use of sample questions that are presented as an iterative planning tool (ADOLESCENCE) to help guide practitioners and interventionists as they plan their own programs. These elements are described further in the following sections.

Accessible

Participants discussed accessibility issues in relation to transportation, hours of operation, convenience, cost of services and childcare provision. Thus there was a perceived need for centres to be located close to public transportation and have flexible hours of operation. In one case, a participant talked about youth infected with HIV through drug using or sexual behavior (‘horizontally infected’) wanting to go after school so that they could be home for dinner and not have to explain where they had been. Internet platforms, in addition to beepers and cell phones, were mentioned as useful technologies to connect young people
to each other, to their providers, and to provide innovative methods of reaching young people with educational materials.

The importance of covering the costs of services was stressed by some participants, especially in the context of the American health services where costs are primarily the burden of the recipient. Participants suggested providing food on site and covering all the costs associated with transportation, childcare, medication, medical and non-medical services. Providing on-site child care makes services more accessible, especially for youth who are single parents.

**Context-Driven**

The importance of context emerged from discussions of program transfer from one setting to another and the importance of contextual factors such as culture, stigma, organizational, and political climate. For example, one participant described how they tried to implement a program that had worked well in mainstream schools into an Indigenous community, with little success. As one expert mentioned: "...whoever does this needs to have… a way of tapping into the culture of the youth in the community where the program is developed and to make sure that there’s a continuous feed of information about that culture."

There are limitations imposed on programming due to structural and organizational barriers such as funding constraints which are partly determined by political will and the HIV infected populations’ ability to self-advocate for resources. Stigma was discussed by all participants and the fear of stigma in part determined people’s willingness to participate in different types of programs (e.g., individual versus group activities). One participant gave
what she considered a unique example of a community where HIV was more prevalent, which she felt that this positively influenced people's ability to be more open about their HIV status.

Approaches to providing services to adolescents with perinatally-acquired HIV varied from setting to setting. Pediatric providers emphasized the differences and separation of perinatally/vertically and horizontally infected populations whereas adolescent providers tended to emphasize similarities and the integration of the two groups. These diverging opinions influenced the extent to which the mature pediatric population accessed adolescent programs. The following emphasized the different viewpoints: “So it’s really the rebellious (perinatally-infected) kids that are more likely to get referred to us because we’re a program that takes care of sexually infected teenagers - even that’s (sexual infection) stigmatized for the perinatally infected kids and their providers.”

Operate Collaboratively

Collaboration is a means of securing additional resources and providing comprehensive care. Participants talked about collaboration in terms of the adult and youth roles in programs. This involved a spectrum of involvement, from mere consultation to involving youth as partners in decision-making. One participant referred to an “evolution”, how this researcher role would change over the course of a project from one that is more directive to a role that is more a consultant or support person. Collaborating with parents was seen by some participants as key in programming for the young people, especially because they can become a strong source of resistance to their children participating in programs.
However this was less relevant for those disenfranchised youth who may have limited contact with their family members.

**Labour/Personnel for Youth**

Characteristics of personnel were thought to be important for implementing effective programs. Most participants mentioned that staff needed to enjoy working with adolescents and that such individuals are sometimes difficult to find and hard to keep:

*A lot of clinicians, have prejudices against teenagers, in general. That they’re somehow going to be recalcitrant, rude, difficult, juvenile delinquents, or take too long to see. Or, you know, a lot of different feelings that way. And so it’s important I think that the actual clinicians like teenagers.*

In some cases, participants mentioned the need for staff representing the diversity of the clients, including ethnic diversity. Some gave examples of the benefits of having younger staff (e.g., research associates) or of hiring youth or HIV-infected peers for their program. As one expert said:

*It’s that we know a lot about behavioural issues and teens and so the expertise of the provider, in adolescent development, and anticipating the types of problems teenagers have in providing anticipatory guidance for teens has been the thing that’s worked well, best for us.*

The attitude and caring of the staff was seen as key to the programs’ success.
Ethical

The ‘ethical’ domain captures ideas of protection, secrecy, and culture in addition to ideas of patient confidentiality. People discussed privacy in terms of private spaces or non-identifying spaces. This overlaps with the ideas of risk and safety or creating safe environments. It was mediated by having rules and education for those clients participating in group activities to ensure the confidentiality of participants as well as for staff. Within programs, strategies were devised such as privacy in offices and the front desk staff not being made aware of the reason for a young person's visit. In another case, the participant spoke about how the families would "get spooked" that someone they knew would see them coming into the hospital or clinic.

Sustainability

Sustainability requires program strategies to address challenges associated with adequate funding, evidence-informed programming, and transitioning. Connecting young people to services and networks offering support over time and helping them through transitional periods was mentioned as vital for successful programs. Adequate funding is necessary to support multidisciplinary teams of clinical staff. One participant mentioned that the "acuity of the cases" is such that each client is very demanding and requires more staff (e.g., psychologists and social workers in addition to medical staff) than other programs.

Assessment and evaluation such as environmental scans and service evaluations are needed to understand the context in which a program will be implemented successfully. Evaluations can be used on a small or larger scale for quality improvement to determine whether or not the program is best meeting the needs of the clients.
Comprehensive

Multidisciplinary teams and ‘one-stop’ shopping models were highlighted as important, especially by more clinically-focused participants. The non-clinical experts tended to suggest youth-driven models. However, the non-clinical participants readily acknowledge the role of clinics and hospitals in enhancing and/or maintaining HIV-infected youths’ health. The participants spoke of teams including not only medical specialists and other clinical professionals in a hospital environment but researchers as well. For some of the participants, these services also included advocacy and facilitating life-skills and group activities.

Youth-friendly Environment

Participants commented that physical spaces (e.g., clinic, community centre) should not be childish or too adult in order for the young people to feel comfortable in their service environment. Space was discussed by participants in terms of protecting privacy, and having objects in that space to accommodate youth. Youth-friendly also included providing a non-judgmental atmosphere and services "reflective of their culture". One participant described the challenges of balancing the needs for nurturing and independence:

*We balance between providing a youth friendly environment but also not creating a sense of entitlement... as well as creating an environment which you know mimics what they would see later on in the health care system... but at the same time I think you know being youth friendly also does mean having a developmental approach and you know people who don’t just assume that teenagers are just littler adults or bigger children. That they are kind of their own group and have special needs.*
Peers and peer advocates were also seen as part of creating youth-friendly services and environment. “Peers” had multiple meanings. For example, one participant clarified "I also am using peers, in the context of cultural peers, age group peers and HIV status peers." A peer advocate position at one of the clinics was one key example of how services can involve peers. This clinical service had a young peer available 24/7 by phone whose responsibilities included accompanying clients to other services, setting up support groups, and keeping track of the client appointments.

**Normalizing**

Normalizing the experiences and lives of HIV-infected young people is linked to what was termed *managing stigma* in one of the guiding questions. There was a theme of having children "get on with their lives" by simplifying medication regimens and participating in mainstream culture and activities so that they feel like they are just like other young people. Examples given of strategies of normalizing services included: integrating HIV-infected youth into mainstream youth services and providing education to the staff in those organizations; taking the focus of programs away from HIV; treating them “like anyone else” (e.g., other children with chronic illness); integrating HIV-infected youth into primary care and social services for mainstream adolescents; and creating programs with non-identifying names with no mention of HIV in the title or resource materials.

**Youth-Centered**

Participants agreed that programs need to meet the diverse and individualized needs of all of the young people by being flexible, using a developmental approach, and through engaging youth in programs. Setting up group activities was an example provided by a
participant: "What is a suitable useful group for one lot, won’t really be for another." Another example was provided regarding individualized stages of young people: "…and people’s development is also quite particular… you might have a sexually active fifteen year old girl who’s very, very mature; whereas you might have a fifteen year old boy who hasn’t even begun to hardly go through puberty yet."

Not all participants agreed that programs should be directed by youth but they all mentioned some degree of youth involvement or participation in the planning or shaping of programs or their care. Clinicians tended to mention how they would involve youth in activities such as making choices about treatment or picking recreational activities. Interventionist researchers tended to talk about this more in terms of creating mentorship and peer-based models of interventions and involving youth in all stages of program and intervention creation. As one expert expressed, "I think young people know what they want and I think if they are consulted and they participate there’s more ownership of those sorts of groups and activities really."

**Discussion**

The framework presented in this paper brings together multiple core elements to form an overarching model for potential use in program planning and evaluation, targeting a specific sub-population of marginalized youth, HIV-infected adolescents. It offers a way of thinking broadly and critically about program planning and evaluation, taking into account social, developmental, and participatory elements. Thus it responds to recent calls for
innovative public health programming that moves beyond the tradition of “objective” and “rational” science to a more reflective, context-dependent paradigm (Potvin et al., 2005).

This paper and the core elements it describes not only acknowledge the need for multidisciplinarity but also partnership between young people, families and their service providers as well as the possibility of integrating academic researchers into both clinical and community programming. The emphasis on the participation of youth in decision-making regarding their own health and the development of the programs themselves represents an important shift in recent years away from previous physician-centered or ‘White Coat’ models (Wear, 1998) of care. Health disciplines such as epidemiology are clearly evident in the core elements described in this paper as they pertain to the professional and ethical delivery of evidence-informed clinical decision-making. In the multiple elements described, there is a move not only towards multidisciplinary teams of professionals but also an interdisciplinary focus; integrating concepts from the social sciences as well as the medical sciences.

Many of the core components identified are supported by other literature and policy papers. For example, the World Health Organization has called for the development of youth-friendly services worldwide. Their guidelines include components such as equitable and accessible points of delivery; private, non-stigmatizing, and safe environments; well-trained and non-judgmental staff; and youth involvement in assessment and provision of services (Tylee et al., 2007). Other authors have discussed issues of program accessibility, (Kang et al., 2003; SAM, 2004) sustainability, (Pluye et al., 2004) collaboration, (Mantoura
et al., 2007; Sullivan et al., 2005) ethics, (Cook et al., 2007; Lesch et al., 2007; Miller et al., 2006) and comprehensive service delivery (Hawe et al., 2004; Huba & Melchior, 1998). However, to our knowledge, these elements have not been unified under a single proposed program model.

With the exception of the Special Projects of National Significance programs in the US which represented 10 demonstration projects targeting HIV-positive and HIV at-risk youth, very little published research is available on existing programs in resource-rich countries for young people living with HIV. Huba and Melchoir (Huba & Melchior, 1998) present a consensus model of adolescent-targeted HIV services for youth at risk and infected with HIV based on 10 program models in the United States. They found that five major elements captured innovations of a collective service model which included: peer-youth information and dissemination; peer-youth advisory groups; peer-youth linked outreach and support; professional, tightly linked medical social support networks; active case management and advocacy for individuals and the programs themselves. The core elements described in this paper complement these types of service models by expanding the scope of assessment to include process and structural elements of program design and success.

Limitations of this study are evident. Primarily, as with most qualitative research, the small number of participants and methodology do not seek to permit generalizability and the results cannot be said to be representative of all expert opinion. Also, this study is from professional ‘expert’ perspectives and does not represent the perspective of consumers of the services themselves. The challenge with any such model is to move it from the theoretical
and academic realm to the area of everyday practice. One of the strengths of this study is that, in directly consulting with experts in the field and providing feedback mechanisms, information is being disseminated directly to relevant stakeholders.

In this study, the inclusion of “normalization” in the professional discourse around HIV-infected adolescents creates a unique nexus between the childhood chronic illness literature and the mainstream HIV care literature. Deatrick (Deatrick, 1988) defines normalization as “the constant process of actively accommodating the changing physical and emotional needs of the child or adolescent”, the goal being to have the child’s life constructed as “normal” as possible. Rehm & Frank (2000) identify goals of normalization with HIV-affected families as: health maintenance for family members with HIV; facilitation of children’s school participation; and enhancement of the emotional well-being of all family members. Normalization is one of the many coping strategies associated with stigmatized conditions (Wong & Wong, 2006) and is particularly relevant to populations of HIV-infected adolescents.

The topic of integration or non-integration of children with perinatal HIV into adolescent HIV services is also particularly noteworthy and timely and has been absent from the peer-reviewed literature. The diverse service contexts and lack of standardized best practices account for wide variability of practices, especially in transitioning children from pediatric to adult care and services. This has implications for whether or not adolescent programs can succeed in including these populations. More research is needed to determine
how this pediatric cohort will access and benefit from existing and future programs targeting HIV-infected adolescents.

In summary, programs targeting HIV-infected adolescents can benefit from thorough planning and evaluation processes that incorporate several core elements. This study identifies and explains 10 such overarching elements arising from discussions with international experts in the field of Adolescent HIV care. It further compiles these components and various subcategories into a question-based ADOLESCENCE planning and evaluation tool. This tool is meant to assist program planners and researchers in designing and refining their own program models. The guiding questions may act as a checklist and can help decision-makers consider and apply the elements that they find most relevant and important in their own clinical or community contexts.
Table 5.1: Script for semi-structured expert interviews

<table>
<thead>
<tr>
<th>Guiding Questions</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Please describe the program(s) for HIV-positive adolescents that you are involved with or have been involved with. What is/was your role in the program(s)?</td>
</tr>
<tr>
<td>2. What are some other examples of programs with HIV-infected children or youth that you are familiar with?</td>
</tr>
<tr>
<td>3. What do you believe are the core elements to a successful program with HIV-positive adolescents?</td>
</tr>
<tr>
<td>4. How do you define program success?</td>
</tr>
<tr>
<td>5. What barriers do you perceive for developing successful programs?</td>
</tr>
<tr>
<td>6. How do you manage HIV-stigma in a program for HIV-positive adolescents?</td>
</tr>
<tr>
<td>7. Are there differences between those adolescents who transmitted HIV horizontally and those who acquired HIV vertically/ perinatally?</td>
</tr>
<tr>
<td>8. Are there any other sources of information or individuals I should look into for further information?</td>
</tr>
</tbody>
</table>
Table 5.2: Select characteristics of expert participants (n=15)

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Category</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td>Female</td>
<td>12</td>
</tr>
<tr>
<td></td>
<td>Male</td>
<td>3</td>
</tr>
<tr>
<td>Country of Residence</td>
<td>US</td>
<td>7</td>
</tr>
<tr>
<td></td>
<td>Canada</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>UK</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Australia</td>
<td>2</td>
</tr>
<tr>
<td>Primary Education</td>
<td>MD</td>
<td>6</td>
</tr>
<tr>
<td></td>
<td>PhD</td>
<td>6</td>
</tr>
<tr>
<td></td>
<td>Masters</td>
<td>3</td>
</tr>
<tr>
<td>Primary Institutional Affiliation</td>
<td>University</td>
<td>6</td>
</tr>
<tr>
<td></td>
<td>Clinical Institution</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>Both</td>
<td>5</td>
</tr>
<tr>
<td>Clinical Services*</td>
<td>Pediatric</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Adolescent</td>
<td>9</td>
</tr>
<tr>
<td>Years working with adolescents</td>
<td>&lt;5</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>5-9</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>10-14</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>15-19</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>20+</td>
<td>7</td>
</tr>
<tr>
<td>Years working in HIV field</td>
<td>&lt;5</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>5-9</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>10-14</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>15-19</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>20+</td>
<td>5</td>
</tr>
</tbody>
</table>

* Not all experts were associated with delivery of clinical services (n=11)
Figure 5.1: ADOLESCENCE Planning and Evaluation Tool: Core elements and key questions in adolescent HIV/AIDS programming

I. Accessible
   A. Transportation: Does the program offer free transportation to participate in activities?
   B. Hours of operation: Is the program available at times when youth are available (e.g. outside of school hours)
   C. Cost: Does the program cover participants’ costs (e.g., medications, recreational activities, food)?
   D. Convenience: Is the location of the program easy for young people to get to? Is someone accessible 24/7 in case of a crisis?
   E. Childcare: Is childcare provided on site so mothers and fathers can easily participate?

II. Context-Driven
   A. Culture: Has the potential impact of community cultural norms, beliefs, and experiences been considered?
   B. Stigma: Has the level of stigma in the community been assessed?
   C. Organization: Have organizational aspects such as hierarchy, policies, and procedures been considered?
   D. Political Climate: Is the political climate conducive to supporting a program in a given community?

III. Operate collaboratively
   A. Youth: Have the youth been involved in decision-making and programming?
   B. Family: When desirable, have the families been informed and involved in decision-making or program development?
   C. Clinic: Are those responsible for the youth’s clinical care involved in developing the programs as consultants or partners?
   D. Community: Is there collaboration with and between community members and groups involved in the implementation of the program?
   E. Research: Have people from the research community been asked to consult or participate in program design, implementation, or evaluation?

IV. Labour/personnel for youth
   A. Like working with youth: Do the staff have experience, knowledge, and enthusiasm for working with young people?
   B. Culturally competent and diverse: Are the program staff trained in working with culturally diverse populations? Are there staff members that are culturally similar to the populations they are serving?

V. Ethical
   A. Anonymity: Are there policies and procedures that guarantee participant anonymity?
   B. Confidentiality: Are there measures in place that protect confidentiality and are these adequately communicated to the participant?
   C. Cultural Sensitivity: Is the program conducted in a way that is respectful of cultural diversity and
issues of access?

D. Protection: Are there policies and procedures that protect participant from harms related to their HIV, minor status, and other vulnerabilities?

VI. Sustainable

A. Supported by Evidence: Are the program elements based on established models or best practices?
   Has there been a needs assessment conducted with the population? Is there a sound evaluation plan and feedback mechanism?

B. Well-funded: Are there multiple sources of funding that can be accessed? Is funding provided on a long-term basis? Is there adequate funding to provide high quality services?

C. Transitioning: Does the program help youth to establish connections (friends, service providers, etc) that will be sustain when they age out of a program? Is there a period of overlap of staff and a gradual move from child to adult services?

VII. Comprehensive

A. Multidisciplinary: Does the program include staff from different disciplines in order to meet a broad scope of participant needs (e.g., psychosocial and medical staff)

B. One-stop shopping: Does the program offer integrated services to facilitate access to more services and participants' navigation of the system?

VIII. Environments that are youth-friendly

A. Space: Do the physical spaces for the program provide an environment that makes young people feel comfortable (e.g., other youth, materials with youth images/messages, computers, video games, magazines, etc)?

B. Peers: Does the program include peer staff?

IX. Normalizing

A. Integrated with other youth: Does the program call for integrating HIV-infected with non-HIV-infected adolescents?

B. Non-HIV focus: Should the program content include HIV-related themes or focus on non-HIV-related themes (e.g. recreation)?

X. Youth-Centered

A. Developmental: Does the program recognize the different developmental stage/range of participants through their activities? Does it acknowledge potentially differing needs of developing girls and boys?

B. Flexible: Does the program have flexibility to meet the individualized needs of the participants as well as those of the group?

C. Participatory: Does the program involve youth in the development and implementation of its program and activities (e.g., through consultation with participants, youth advisory boards, etc)?
References


Fielden, S., Sargeant, S., Grant, S., Chapman, G., & Frankish, J. (2008). The HYCUP project: Development of a community-academic health promotion partnership serving adolescents living with perinatally-acquired HIV. *The Canadian Journal of Infectious Diseases and Medical Microbiology, 19*(Suppl. A), 12A.


Chapter 6: Managing Stigma with HIV-positive Adolescents: Silences, Secrets, and Sanctioned Spaces

Introduction

Despite great improvements to population health and well-being resulting from global efforts in HIV prevention, care, and treatment, the “fight against AIDS” is still haunted by an enduring HIV stigma and its harmful effects on those living with the virus throughout the world. HIV stigma reportedly prevents people from seeking HIV testing, accessing medical care, adhering to medications, and participating in programs designed to enhance the health and well-being of those affected by the disease (Chesney & Smith, 1999; Herek 1999; Rao et al., 2007; Vanable et al., 2006). HIV stigma has been reported to be prevalent among children and adolescents (Dias et al., 2006; Gonzalez-Rivera, 2007). Children as young as 10 years old have visually depicted people with HIV as physically deteriorated and performing socially condemned behaviors as well as recounted stories that illustrate fears about contracting the virus (Gonzalez-Rivera, 2007). Historically, illnesses and stigma have been intimate bedfellows, especially in the presence of contagion such as in the case of cholera or TB (Herek, 1999). However, the etiology of HIV brings new fervor to the illness-stigma relationship and arguably amplifies it through ‘symbolic’ associations, thereby adding to the complexity of sexual taboos and moral judgment (Crandall et al., 1997).

Young people are one of the populations that will be most affected by HIV stigma. People under the age of 25 make up almost half of new infections worldwide (UNAIDS,

22 A version of this chapter will be submitted for publication. Fielden, S.J. Managing stigma with HIV-positive adolescents: silences, secrets, and sanctioned spaces.
23 HIV related stigma gains its power from ‘symbolic’ attitudes towards already stigmatized groups and from ‘instrumental’ fears of infection (Crandall et al., 1997).
HIV-positive adolescents, both those who acquire HIV at birth (vertical) and those who become infected later on in life through behavioral (horizontal) routes of transmission, are exceptionally vulnerable as populations. Many are economically and socially marginalized either as part of disadvantaged families and/or as disenfranchised “emancipated”\textsuperscript{24} minors (DeMatteo et al., 2002b; Rogers et al., 1996; Rotheram-Borus et al., 2001). Rapid transitions, physically, psychosocially, and culturally, further contribute to their vulnerability as does the general lack of youth-friendly programming and health services to help them navigate the route to health and wellness in adulthood (Tylee et al., 2007).

HIV-infected adolescents born to HIV-positive parents will have unique stigma experiences connected to their childhood experiences of disclosure within the family. The American Academy of Pediatrics (1999) supports disclosing to children about their HIV-positive status as part of a process that works with the child’s developmental stages. While adults and adolescents with horizontal HIV infection receive their diagnosis from their physicians, HIV disclosure for those vertically infected is often left to parents who will take various approaches on a continuum of complete disclosure and complete non-disclosure (Funck-Brentano et al., 1997; Salter-Goldie et al., 2007). Reasons for non-disclosure cited in the literature include: guilt; not wanting to burden children with the stigma of the disease and possible social rejection; wanting the child to live ‘normally’; and fearing the child’s inability to ‘keep the secret’ thereby risking exposure of not only the child’s but also the mother’s and/or other family members’ HIV status (Lesch et al., 2007; Lester et al., 2002; Waugh, 2003; Weiner et al., 2007). Conversely, reasons for disclosure to children include a desire for

\textsuperscript{24} An “emancipated minor” is a legal status that exists for those who are living apart from and are independent of their parents/guardians (Weddle & Kokotailo, 2002).
honesty and trust within the family; having a child rights approach; parents feeling that
children were ‘old enough’ and developmentally ready; and wanting children to participate in
decisions about their health and enjoy social opportunities (DeMatteo et al., 2002a; Lesch et
al., 2007; Lester et al., 2002; Waugh, 2003; Weiner et al., 2007).

The literature describes instances of blatant discriminatory acts against young people
and families living with HIV such as being refused entry into daycares, schools, and extra-
curricular groups such as a Girl Guide troupe (Adolph, 1994; Herek, 1999; Weiner, 2000).
Studies of young people living with HIV have shown an association between stigma and poor
mental health, less social support, and stress from having to continually manage social
relationships and disclosure (Swendeman, et al., 2006). Hosek (2002) found that stigma may
cause HIV-positive adolescents to postpone educational and vocational goals. They may feel
discriminated against by family and friends and choose to keep their HIV status a secret (Rao
et al., 2007), thereby further isolating themselves and cutting off sources of support.

In resource-rich countries such as those in North America and the European Union,
health and social services work to promote the health and wellness of children, adolescents,
and families living with HIV. Specialty clinics with multidisciplinary teams of HIV medical
and psychosocial specialists tend to be located in urban areas and are often complemented by
linked social programs that deliver services such as support groups and recreational outings
for HIV-positive children and adolescents.
During the course of a multi-step research project aimed at designing a health promotion program model targeting HIV-positive adolescents, the issue of stigma emerged as a key theme of program design with this group. This paper explores health service providers’ understanding of the stigma experienced by HIV-positive adolescents and how these experiences are managed through ‘silence’. It extracts key themes, using the perspectives and experiences of professional service providers who participated in the larger study and draws on social theory to open up these themes to more thorough conceptualization and critique. These themes need to be understood within the broader context of HIV stigma, the inequities associated with a ‘minor’ status, and public health strategies used to manage HIV stigma.

**Background**

**HIV Stigma**

Using Goffman’s seminal work (1963) stigma can be defined as an “attribute that is deeply discrediting” and that reduces the bearer “from a whole and usual person to a tainted, discounted one.” Stigma involves both an attribute and the social assumptions and responses associated with that attribute. In Link & Phelon’s (2001) framework, stigma is a co-occurrence of: labeling of the ‘other’; linking this to negative stereotypes; separating ‘us’ from ‘them’; a loss of status and discrimination by ‘normals’; and, underlying these, the power that allows one group to subjugate another. The issue of power is paramount as stigma cannot exist without the hierarchies that permit ostracism and marginalization to occur. Individualistic notions of stigma are inadequate in terms of capturing the multi-level or multi-systems nature of stigma and therefore many authors emphasize the social and structural forces at play in its creation, manifestation, and impacts. Stigma has been described as “an arbitrary and cruel form of social control” (Burris, 2008, p. 475) and may be viewed as
a social process imbued with ability to produce and reproduce inequities, located at the meeting place of culture, power, and difference (Parker & Aggleton, 2003). HIV stigma is the stigma specifically targeted towards those people living with the HIV virus. This stigma is associated with the severity and contagion of the disease, misunderstandings and ignorance about the mechanisms of HIV transmission, and discriminatory attitudes towards social groups that are disproportionately affected by HIV (Herek et al., 1999).

HIV stigma, like other forms of stigma, may be conceptualized as “felt” or “enacted” (Bogart et al., 2008; Scambler & Hopkins, 1986) distinguishing between the internal psychological processes of the individual (or stigma target) and the actions of the perpetrators of stigma. “Internalized” stigma (Steward et al., 2008) is part of felt stigma and represents a possible reaction to the experience of stigma that may turn stigmatized people against themselves through a phenomenon of self-oppression. Burris (2008) argues that what is worse than the cultural alienation that stigmatized people often face is this self-enforcement that turns individuals into their own “jailors”, their own “chorus of denunciation” and which takes “inhumanity to an ultimate pitch” (p. 475). In HIV, experiences and feelings of stigma threatens the health and quality of life of adults and children living with the virus (Herek 1999; American Academy of Pediatrics, 1999). The individual’s experience of HIV stigma is embedded in a discourse about health and illness that is ever-changing according to historical and cultural norms and illness progression. This latter point is illustrated by Alonzo & Reynolds (1995) who locate HIV stigma along a trajectory that parallels stages of illness (at risk, diagnosis, latent, and manifest) and conclude
that the internal, social, and ideological experiences of HIV stigma will differ according to where a person is located along this trajectory.

**HIV Stigma and the Minor “Layer”**

HIV stigma often follows in the footsteps of existing social exclusion, delineated by characteristics such as race, gender, and identified “risk” groups (e.g., male homosexuals, female commercial sex workers, and intravenous drug users). These inequities lead to what is commonly referred to as a “layering” of stigma and to what Herdt (2001) refers to as the creation of the “superstigmatized”. This will produce considerable variation in how people experience the stigma associated with being an HIV-positive person. A “layer” that remains unarticulated and unexplored in the HIV literature is that of the “minor”. One of the few studies to look at HIV stigma in minors is the work of Abadia-Barrero and colleagues (2006) who examined HIV-infected and HIV-affected orphans’ experiences of stigma using an ethnographic research approach. The research was conducted with children aged 1-15 years living in San Paolo, Brazil in two child “support houses” (Non-Governmental Organization shelters). The authors argue that children’s experience of stigma is fueled by structural violence in the forms of poverty, racism, and inequalities in social status, gender, and age; they conclude that several discriminatory processes, rather than isolated forces, act together with HIV/AIDS in the lives of the children.

HIV is a sexually transmitted disease and as such carries with it the general taboo of sex. Child and adolescent sexuality has a double taboo since sex among minors is not

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25 “Layering” of stigma however should not reinforce a hierarchy of oppression but illustrates the complexity of inequities experienced by youth as a function of age and developmental status.
perceived as natural or acceptable by many adults, especially parents. Adolescents living with HIV are in a difficult and volatile position, needing quality information and support around HIV and their sexual health but having diminished capacity to access resources independently and few people who are willing to offer support to them around sexual issues. The way a family experiences a case of HIV in adolescence will depend on the mode of HIV transmission, vertical or horizontal. While HIV-positive adolescents with horizontal transmission will have some choices about the role of family in their HIV diagnosis, children and adolescents born with HIV will have their experiences and knowledge of HIV/AIDS and its stigma facilitated through the adults in their lives. One could argue that adolescents born with HIV may have a slight advantage over those who contracted the virus through behavioural means since they may be perceived as ‘innocent victims’ of the disease. In these cases, the HIV-positive mother likely bear the brunt of the stigma, as she is further demonized and held ‘responsible’ for the infection.

If stigma thrives and multiplies in the presence of social inequities, then minors as a function of their lack of power, personhood, and their status as incomplete citizens will be some of the most vulnerable to its effects. Although policy documents such as the UN Convention on the Rights of the Child advocate children’s participation in decisions that affect their lives and health, children and adolescents have few legal rights. Most HIV-positive minors will be embedded within their families, biological or otherwise, with adults authorizing and monitoring their daily activities to a greater or lesser extent.
HIV Stigma Management

Stigma management is conceptualized here as the shifting or manipulation of internal and external processes in order to address stigma in a given situation or setting. Reactions to HIV stigma reported in the literature include individual strategies of denial, silence, lying, and other coping mechanisms of HIV-positive people (Sandelowski et al., 2004; Steward et al., 2008). HIV stigma will be managed in the lives of HIV-positive adolescents by various people, including parents, health care providers, and other people who may have knowledge of the HIV diagnosis. Public health and health promotion practitioners have reacted to HIV stigma through creating interventions that attempt to reduce it (Heijnders & Van Der Meij, 2006). In these ways stigma is managed by the individual and by the more powerful institutional and structural forces that work to change felt and enacted stigma towards people living with HIV.

Stigma interventions seek to address the problem by targeting the “targets” and/or “perpetrators” of stigma. However there is little documentation of such interventions. In his review of 22 studies testing interventions to decrease AIDS stigma in developed and developing countries, Brown and colleagues (2003) found that most interventions aimed to increase tolerance of persons living with HIV/AIDS among the general population. Other studies aimed to (1) increase healthcare providers’ willingness to treat people living with HIV or (2) improve the coping strategies of HIV-positive people for dealing with stigma. Types of interventions were divided into information-based approaches, skills-building, counseling, and ‘contact’ with affected groups (e.g., contact with HIV-positive individuals one-on-one or through visual media). Although none of the studies targeted HIV-positive minors, eight sought to work with school-aged children to create more positive attitudes.
towards people living with HIV/AIDS. Lyon and Woodward (2003) describe a program model that they described as effective for overcoming stigma with HIV-positive inner city African American adolescents. This involved identifying seven program elements including: adapting proven programs; involving the youth in program creation; avoiding stigmatizing labels; being culturally-sensitive; focusing on healthy living rather than the disease; removing practical barriers and providing incentives; and creating interventions that were skills-oriented with tangible benefits. However, large gaps exist in public health management of stigma with most interventions showing only small scale and short-term success (Brown et al., 2003). The question remains: how is stigma understood and managed by the professionals who work with HIV-infected adolescents and their families?

**Methods**

This study was part of a multi-step project to design a health promotion program model targeting HIV-infected adolescents, including those with perinatally-acquired HIV (Fielden et al., 2008). The research was approved by the Behavioural Ethical Review Board of the University of British Columbia (Appendix A).

The research methodology was guided by constructivist qualitative inquiry and employed individual, semi-structured interview techniques (Miles & Huberman, 2004) to obtain rich and comparable data about key considerations from the perspective of professional service providers/interventions in the area of Adolescent HIV programming. Qualitative research is increasingly being used in health service programs and policy research. Its methods are useful in generating theoretical and empirical knowledge about
social processes, cultural knowledge, and peoples’ understanding of their everyday lives (Pope & Mays, 1999; Strauss & Corbin, 1998). Participants were selected purposively based on their clinical and/or research experience in the field of Adolescent HIV and via snowball sampling. Interviews were conducted by telephone and included open-ended questions to deepen understanding and allow space for rich description. Fifteen service providers agreed to participate in the study. The group was disproportionately female and almost half (seven) of the participants were from the US followed by Canada (four), the UK (two) and Australia (two). All participants were professionally trained and educated with the majority holding either an MD or a PhD in a health-related field. Most were directors of adolescent HIV services and/or appointed university faculty members. They were health service providers (e.g., physicians, social workers, community or academic interventionists). Over half of participants had 15 years or more of experience in the fields of HIV and Adolescent Health, and some had been working with HIV-infected adolescents since the beginning of the HIV epidemic in 1981. Further details of the study, its participants, and its methods can be found elsewhere (refer to Chapter 5).

Participants were asked to describe the programs with which they were historically or presently engaged, to reflect on the core elements for successful programs with HIV-infected adolescents, and to expand on barriers to programming. Participants were asked questions that probed the topics of stigma and stigma management in the context of their programming and experiences with HIV-positive adolescents. Transcripts were entered into NVivo 7.0 (QSR International) qualitative software to facilitate coding, comparison, and overall data management. The analysis of all the interviews included memoing (Miles & Huberman,
1994) about the evolution of coding categories and maintaining a reflexive journal to record questions, key concepts and other considerations arising during the analysis. Analysis initially used line-by-line coding of the transcripts to identify codes and to create a coding framework. Transcripts were subsequently coded through “chunking” the data, and by coding for individual questions and text queries (Miles & Huberman, 1994). The coding sought to decontextualize the data through identifying and grouping themes and to recontextualize the data through examining the locations of overlap and where the themes coalesced. To move beyond the content and thematic analysis and to examine the complex and relational issues of adolescence and HIV stigma, the analysis relied on social theories to help connect power and developmental issues to experiences and communication surrounding HIV/AIDS.

Results

Stigma emerged as a thematic thread throughout all the narratives with participants often offering up examples as they referred to events occurring in the lives of HIV-positive adolescents. It was discussed both in response to direct questions and the examples they provided in the overall interviews. Related codes demonstrated how stigma manifested itself through the mediation of various actors and spaces embedded in the reality of the adolescent. In these results we present the data using excerpts of professionals’ accounts of their clients’/participants’ experiences. We suggest that HIV stigma manifests itself through various ‘silences’ that surround HIV in the adolescents’ lives and through the normalization of the illness experience by adolescents, families, and healthcare providers.
Silence is a tool for both protecting against stigma and guarding secrets. Silence is generally a more neutral term than “secrets” and “stigma”. Although we often see silence portrayed negatively in HIV discourse, exemplified by slogans such as ACT NOW’s “silence=death” and “breaking the silence” (used as the title for the 1999 International AIDS Conference), it has other popular meanings. It exists in a communication/linguistic dichotomy with the phenomenon of ‘voice’, yet both may be used as tools for resistance (e.g., the silent vigil). Silence may indicate respect for others, reflection, or listening. It may exist innocently and comfortably between people. In short, it is not always symbolically malevolent. Silence is also a less bounded concept. Whereas secrets and stigma imply human action, silence can linger in spaces, it can be fluid and disembodied. It can hang thick in the air, weighted down with what goes unsaid, or lightly float carelessly in the spaces between. Silence is found in the various environments and spaces that make up the HIV-positive adolescent’s lived experience. These silences may be likened to ghosts who, according to Piles’ (2005) “ghostly city”, take possession of domestic spaces and stand at the threshold of the personal and the social. This study exposed three social worlds where silence was evident, as expressed through the service providers’ discussion of stigma management: the world of the child; the world of the family; and the world of the provider.

**Silence in the World of the Adolescent**

According to participants, adolescents living with HIV experience isolation, fear, and shame as a result of their HIV-positive diagnosis. Once they learn about their status, adolescents living with HIV will need to make difficult decisions about whether or not to stay silent or disclose to friends, sexual partners, family members, and other significant
HIV-infected young people talk about having two worlds or two bubbles... They have one world that’s their normal world that they function and interact with. And then they have their HIV world. And if you ask a lot of young people “who’s in that world with you?” the HIV world, a lot of them will say “I’m actually on my own in that world.” ...they’re saying very clearly that you either have two worlds or two bubbles or two boxes... and I say well “who’s in there (their HIV box)?” And they say no one’s in there and the door’s shut.

Participants reported that many young people choose to be silent rather than to disclose their HIV status to anyone in their social networks. Young people can feel tremendous pressure around decisions about staying silent or deciding to reveal their ‘secret’. Participants explained that many of the young people they work with chose not to disclose their HIV status to anyone. They used terms such as “fear” and “terrified” when referring to the adolescent’s feelings around disclosure. This silence was situated within the context of personal and/or professional relationships and opportunities such as a child who was failing in school yet was unwilling to tell school personnel of his HIV-positive status which was the reason for his multiple absences. A provider gave the following account involving a young man who was struggling to disclose to his long-term sexual partner:

Because at what juncture does it become safe? When do you trust someone sufficiently enough to say, “yes I know you want to sleep with me but, by the way, this is what I’ve got.” And you know several of the young people say “well, just watch
how fast they can run out of the door.” And obviously that’s happened to a lot of them… So you know it’s led other young people to say “well, actually I’m not going to tell.” One young man is about 17 and he’s having sex with a condom with his girlfriend. They’ve been together about a year. She now wants to have a baby and he hasn’t told her that he’s infected…And he’s saying “what do I do now? I’ve known her a year. How can I now tell her?” So he’s using every excuse that he can imagine, he can dream up, of why he needs to wear a condom because he’s really struggling with how to actually disclose to her now because they’ve been together over a year and the issue then becomes, when you’ve known someone for a long time, then you fear losing them as a friend because they may feel hurt that you didn’t trust them in the first place.

Participants also talked about the dilemmas for the young people in terms of telling their peers about the diagnosis. Issues expressed by participants generally fell into two conflicting categories: young people’s fears about rejection and discrimination if they chose to tell versus their loss of potential sources of support and wellbeing if they chose not to tell. Examples were provided of young people who have had their friends “stick by them” after disclosure of their HIV-positive status while other providers told stories about adolescents who had been socially rejected by their peers after disclosing their diagnosis.

*The kids don’t necessarily tell their friends that they have it (HIV). Or they’re afraid to tell potential sex partners that they have it. And they’ve been warned all their lives to keep this a big secret and all that ends up isolating them.*
Silence in the World of the Family

Participants who worked primarily with adolescents who had acquired HIV horizontally tended not to speak of the world of the family except in reference to adolescents not disclosing their HIV status to family or not having a positive relationship with their parents.

*We* encourage, support adults to be included if they’re around and if it will be a benefit to the young person. And it’s getting better in the modern day. But I can tell you, 15 and 18 and 20 years ago it was not the case. And so often times the discrimination even amongst families was so great that it was better for teenagers sometimes to be on their own.

In contrast participants extensively discussed family issues for adolescents born with HIV. In the case of adolescents living with perinatally-acquired HIV, like other chronic diseases diagnosed in childhood, the parents or guardians are made aware of the child’s condition before the child themselves. Participants in this research indicated that families take various paths to disclosure and have many hesitations about telling their children the diagnosis.

*There are parents who don’t even talk with their kids about it* [the child’s HIV status]. *They lie to them about what they have in the first place and when they do finally disclose they’re very hesitant to discuss it at all. Which is difficult because these kids have real concerns that they might want to discuss with their parents. I think what then sometimes happens is kids, they get this idea of secrecy and that they can’t tell anybody. So then they don’t tell their sexual partners, they don’t tell their*
close friends who could be real supports for them and in fact they lie to them about what they’re doing...

Issues of power and inequity arose from discussions of legislation surrounding requirements for parental/guardian consent when it came to the sexual health of the adolescents. This consent could be a barrier especially when young people were not in the care of their parents but were cared for by other adults such as being wards of the state. Parents were described as potential barriers in terms of the adolescent accessing programs such as support groups or recreational camps. Some providers discussed strategies of involving parents/guardians in programs while others discussed the disempowering effect that adult control could have for young people as illustrated in this quotation:

[I] think because the parent is a stronger party and the more vocal party, children’s needs get mediated through an adult, rather than them being looked at as an individual... And I think it’s very difficult for a nine or ten year old to say: “hang on a minute I’m here.” I think they’re in an environment where things are being done to them, they’re being talked about... They’re not empowered to be able to say what they want to say. And most children don’t want to upset their parents anyway...

Silence in the World of the Provider

Service providers often act as mediators between the silence and the telling of the ‘secret.’ They provide education and support to HIV-positive adolescents and families and may be some of the only people with whom adolescents discuss HIV-related issues and concerns. Participants described how they helped parents/guardians disclose to their HIV-positive children and how they assisted young people to disclose their HIV status to sexual
partners. Although some providers supported disclosure to significant people in the young people’s lives they also encouraged selective disclosure so as to protect the young people from stigma.

...we don’t actually actively encourage them to inform people because our experience has been that for those young people who have told their friends and told their teachers, that basically, the information just gets passed on and everybody finds out... because it’s still such a stigmatized condition, at the moment that’s just not to their advantage. However we very strongly encourage them that it’s in their interest for the local services to know. So for their general practitioner, or their health visitor, the primary care team, be aware of their diagnosis... we talk a lot with families and we always want them to be able to be open to us about what their worries are.

I think you need to have talks with kids about disclosure and role playing around disclosure and deciding who you’re gonna disclose to and who you’re not gonna disclose to but I certainly don’t encourage kids to keep it a really big secret.

Support and educational programs described by participants included medical and psychosocial programming. In the delivery of programs such as recreational outings, providers may choose to maintain silence with the intention of reducing the stigmatization of the young people. In one example, a pediatric provider explained how she would speak to the people in charge of a recreational activity (e.g., horseback riding) to assess whether or not it would provide a comfortable stigma-free environment for the young people. In other cases, she would choose not to inform the service or to tell a partial truth, indicating that children
had an immune-related illness. In this way, providers may be intermediary agents in the private and public lives of the HIV-positive adolescents.

**Managing Silence**

Managing stigma entails managing the disclosure and silence in the lives of the HIV-positive adolescents. It is about deciding who can and cannot be told, how best to tell, and under what circumstances the silence can be broken. When asked to reflect on how they managed HIV stigma with adolescents they worked with, participants brought up strategies that worked with negotiating more individualistic issues such as providing skills and tools for disclosure as well as strategies for creating non-stigmatizing environments and working to decrease stigma in the community.

*I think they (HIV-positive young people) need tools and I think they need words to practice doing it (disclosing). So that actually they can develop some of the skills to learn how to actually tell people because I think it’s all very well being shown how to put on a condom and all the other issues around safer sex. But actually having that conversation and knowing what words to use and how to say it I think they actually need help and support in doing that… I think it’s very hard to find the words.*

Strategies for dealing with stigma often involved creating what some called a “safe space” for adolescents living with HIV. Safe spaces were described as physical space, such as the physician’s office, or social spaces where the adolescent could avoid stigma by either being among other HIV-positive adolescents and accepting ‘others’ or by being anonymous. A few participants mentioned using the internet as a tool to create non-identifying cyberspaces that would allow young HIV-positive people to connect to others and receive
support and education. Safe spaces were described as places where adolescents could either feel comfortable and open about their HIV status or conversely, feel that they blended in with HIV uninfected-peers.

Well that’s what I had said about needing the clinic setting to be able to assure privacy and confidentiality. Because behind closed doors, of course you know the conversation is wide open. And it includes those words HIV, and AIDS and so forth. But in a big waiting room and, calling people in, or conversing in the hallway where people are maybe walking by, we just are careful about what words we’re using.

Silence was obvious in how participants described their management of stigma in the clinical and program planning settings. Providers used silence to create safe spaces, which most often entailed eliminating HIV from aspects of their practice through deliberate use of non-identifying signage/labeling, and integrating HIV-infected adolescents with adolescents with other health conditions (e.g., asthma). The latter strategy would seem to have the dual function of not identifying that certain adolescents have HIV but also ‘normalization’, making the adolescents feel like they are just one of many young people attending an adolescent clinic.

Some participant discussions extendinh non-identification to spaces such as the clinic waiting room or to non-clinical staff. For example, one participant said that the registration staff did not have access to information about the adolescents’ conditions. All of the participants stressed the need for spaces to be non-identifying, with no mention of “HIV” or “AIDS” at the sites where the young people received their primary health care services.
We’re conscientious of signage: it’s important that there not be some kind of sign or poster, designation that only one kind of disease entity is seen in one office or one side of a clinic. For instance in ours (our clinic), it just says “Adolescent Medicine.” There are no signs that say anything about sexually transmitted diseases, HIV, any of that, because the HIV program is located in the same area where teenagers with other diseases are seen as well.

...well when our kids come in for care they’re coming as part of a busy, adolescent clinic, and so they’re not, necessarily, identified to anyone sitting in the row, in the waiting room as being any different.

So you’re always trying to, no matter where the kid is in the hospital, minimize that association of why they’re here. So even the suite where the social workers and psychologists sit etcetera, outside of the suite, isn’t identifying in any way... while you can certainly get information, disease specific information within the suite.

As one of the providers explained, the goal was not to “sanitize away the concept of AIDS” but rather to create safe spaces where young people would come to discuss their health. This statement exemplified the severity of HIV stigma perceived to be felt by young people and implied that HIV needed to be ‘erased’ in order for adolescents to access much needed primary and social care services.
Interpretation

Silence has been described as one of the common reactions to HIV stigma and as a strategy of concealment, along with lying, passing and circumventing the need to disclose (Sandelowski et al., 2004). The results obtained from the service providers in this study illuminate various morphologies of silence in the lives of HIV-positive adolescents. Silence permeates the minor’s experience of HIV stigma. Individually, silence may be seen as both an oppressive, stifling consequence of HIV stigma and a way for young people to resist the impact of this stigma on their lives. Professionally, silence is a tool that is used to manage stigma and to “normalize” the lives of HIV-positive adolescents, perceived as protective against the deleterious effects of ignorance and prejudice.

Managing stigma has been said to have become an issue of managing disclosure (Letteney & LaPorte, 2004). This paper takes this argument one step further by maintaining that managing stigma is also about managing silences. It moves beyond disclosure, beyond verbalization and the micro-communication between people or groups of people, to include what goes unsaid, unseen, and undetected. The silences illustrated in this paper are embedded within a set of social and cultural rules that create various discourses and spaces, governed by a complex set of power relationships. These are illustrated through participant narratives about the role of silence in programs and the social realities of the adolescent including the ‘worlds’ of the adolescent, the family, and the provider. The following discussion elaborates on these issues through highlighting the relationships between: silence and power, silence and spaces, and silence and secrecy in the lives of HIV-positive minors.
In The History of Sexuality (1978), Foucault argues that “there is not one but many silences, and they are an integral part of the strategies that underlie and permeate discourses” (p. 27). In discussing the topic of human sexuality, he rejects the notion that sex has simply become silenced in society and suggests instead that we examine who is and who is not allowed to speak, the form and context of such speech, and the power dynamics and structures that give rise to certain ways of speaking. Silence becomes managed within disciplines and institutions such as medicine and psychiatry as well as in the home and within the family. In terms of the silence said to surround sex, Foucault searches for “discursive production” (that can administer silence) and the “production of power.” In the case of adolescents living with HIV and the associated stigma(s), discourses and power operate at multiple levels including the stigma “layer” of the minor. In this paper, through the participant narratives we can see how power operates through the adult-adolescent relationship with parents/guardians and professionals making decisions for and speaking on behalf of the HIV-positive adolescent. The responses of the professional participants expressed in this paper are themselves illustrative of existing power dynamics, as their perceptions of the adolescents’ realities depends on what occurs within an adult-adolescent relationship with them positioned as authority figures. The ‘expertise’ that the providers possess regarding program delivery for HIV-positive young people is a function of their powerful role in service provision as adult decision-makers. This power is also what makes it possible for them to speak openly about the experiences of this population, whereas the young people themselves remain silent as decision-makers and as narrators of their own experiences.
Herdt (2001) explains that stigma threatens the human rights associated with “personhood” and “citizenship.” However minors, through their exclusion from social and political decision-making lack these rights and associated social power from the outset. As Gordon and Paci (1997) discuss in their work with cancer patients, silence and concealment are styles of communication that flourish around hierarchy and help sustain social unity and embeddedness. This study pointed to differences in power and knowledge between professionals who managed medical and social programs and family members; and between adults and adolescents. Whereas healthcare providers exist in a world where HIV is readily discussed and where research, conferences, and medical discourse make HIV highly visible and a topic for discussion, adolescents and their families have few places where they can talk freely about HIV. Other authors have discussed how parents and adolescents have difficulties even naming HIV (Hosek 2002; Waugh 2003). In a qualitative study of identity development among HIV-positive adolescents, Hosek (2002) states that one of his most notable findings was the absence of direct reference to HIV and the frequent use of euphemisms (e.g., “my situation”) during interviews, which was thought by the author to serve a self-protection function. Accounts by the participants in this paper reinforced that HIV-infected adolescents rarely discuss HIV and that there are few spaces considered “safe” for speaking about it.

Silences exist at various levels for adolescents including the intrapersonal, interpersonal and in the family and community spaces. It exists in the adolescents’ personal space as they struggle to incorporate HIV into their lives and developing identities, in the spaces between the adolescents and their friends, lovers, family members, and social and community networks and in physical spaces of the home, clinic, and community. In this
paper we see a connection between silence and erasure, with providers creating non-identifying spaces for clinical and social programs to occur. By erasing what Goffman (1963) refers to as the “stigma symbols”, or visual reminders, spaces participate in managing the HIV stigma. By integrating HIV-positive adolescents with other adolescents with various conditions, the providers wish to create a ‘normalizing’ environment, where no one condition is singled out and where HIV-positive adolescents do not feel ‘different’. It would seem that for most of the participants, “safe space” meant non-identifying space. However, this strategy seems somewhat contrary to those used for other stigmatized groups or conditions where creating “safe spaces” entails letting adolescents know that their difference is accepted by using symbols rather than eliminating them. For example, Kreiss and Paterson (1997) describe how primary caregivers can create safe spaces for lesbians, gay, bisexual and transgendered youth by having gay-friendly books on office shelves and fliers on the walls.

Goffman also refers to “information control” and explains how the stigmatized persons can sometimes “pass” for normal. He distinguishes between the “discredited”, those with a “mark” that is fairly obvious to others (e.g., physical disability), and the “discreditable”, those who have characteristics that can be hidden from sight but, when revealed, would make them become discredited (e.g., addiction). Scambler (1998) adds to this argument by stating that the discredited engage in “impression management;” whereas the discreditable engage in “information management”. Both of these may apply to HIV-positive adolescents, depending on their stage of disease and the strategies used to conceal. Some of these strategies of erasure used in the clinic and community may be likened to
structural forms of “passing”, efforts to ensure that, from the exterior, HIV-positive adolescents and their environments were seen as more ‘normal’.

Silences that exist for the adolescent, as described by participants in this study, reinforce the findings of other studies that many adolescents living with HIV experience social isolation and fears about disclosing their status to significant others, family members, and people in their social and community networks (Abadia-Barrero & Larusso, 2006; D’Angelo et al., 2001; Fernet et al., 2007; Rao et al., 2007); even though that social support can often act as a “psychological buffer” against mental health problems (Lam et al., 2007). Silence is described by Bok (1989) as the “first defense” of secrets. Adolescents infected with HIV will typically keep secrets about their seropositive status, secrets held within the adolescent and sometimes within their families as a ‘family secret’. Their secrets are guarded by those who work closely with them such as their clinicians and those in the community who work to meet their HIV-related needs. Bok states that the defining feature of secrecy is intentional concealment and she notes that both inside (that which individuals may forget, repress, or ignore) and outside powers may be responsible for keeping people “in the dark” (p. 10). On the topic of children and secrecy she theorizes that it is “not through any one aspect of experience but throughout the growing consciousness of self and others” that people come to learn about secrecy. In the case of the HIV-positive adolescents who were the focus of this study, they seem to come to learn about secrecy (and the tool of silence) through what was said and unsaid as well as other signs and symbols in their lives. They will learn about it from what they see and hear in school from teachers and peers, from the media and television, and through other significant relationships in their lives. For those infected as
children, adolescents living with HIV may also learn about secrets through the modeling and the paths of disclosure chosen by their family members.

‘Secrets’ are especially ubiquitous in the pediatric and family HIV literature where secrecy is often described in terms of parental readiness to disclose an HIV diagnosis to their children. The literature is populated with many studies reporting poor disclosure rates, even with older children and adolescents. Studies have shown that more than half of perinatally-infected adolescents were not informed of their illness (Thorne et al., 2000; Lee et al., 1999) with other studies reporting rates of approximately 50-75% (Thorne et al., 2002; Lester et al., 2002). One study reported that some of the adolescents with perinatal HIV infection actually became sexually active before they learned of their HIV status from parents or providers (Ezeanolue et al., 2006). Tasker (1992) describes four stages of readiness in HIV status disclosure: secrecy, exploratory, readiness, and disclosure. Salter-Goldie et al. (2007) reported using this staging to work with families to encourage disclosure to children through pre-disclosure preparation, disclosure, and post-disclosure tools. These include strategies such as partial truth-telling, where children may be told they have an illness but without acknowledging that it is HIV/AIDS and encouraging parents to teach their children discretionary skills in order to help them ‘keep the secret’. The latter may also be compared to Scambler and Hopkins’ (1986) work exploring stigma in epilepsy and what they refer to as “stigma coaching,” when influential ‘allies’ like parents teach young people to avoid stigma.

The silence that exists in the family poses serious ethical and legal dilemmas when the various actors’ rights and responsibilities become blurred. Issues surrounding HIV
disclosure to children are located at an intersection of human rights: the rights of the child to participate in decision-making regarding their own health, the rights of the parent to protect and raise their children but to also potentially protect the confidentiality of their own HIV diagnosis; and the rights of the clinicians and other providers to protect their program participants (e.g., parent and child patients) against harm while promoting public health.

This paper highlights the complex nature of silence as it relates to HIV stigma in adolescence and joins the call for interventions that address stigma at various levels and that consider structural forces and inequities, including minor rights (Abadia-Barrero & Castro, 2006; Ayres et al, 2006; Link & Phelan, 2001). HIV programs and policies for HIV-positive adolescents can be enhanced through considering the silences in their realities and the way stigma is managed by the different actors in their lives. Further research is needed to explore how adolescents learn about and internalize HIV stigma and to explore other management strategies used to decrease stigma in this population. Research needs to identify the spaces where adolescents experience stigma and explore the moments when these young people feel most comfortable. It needs to elucidate in which spaces naming HIV is acceptable or safe, and in what ways silence protects against or reproduces stigma. Health service providers need to work collaboratively with adolescents and their significant others to develop successful interventions, creating “safe spaces” where young people feel comfortable voicing their concerns and naming HIV. This may include spaces of ‘resistance’ against oppressive forces of stigma, such as the cyber spaces mentioned by some of the participants, whereby young people can openly discuss their HIV-related issues anonymously. Events such as disclosure to sexual partners must be understood within the history and context of how young
people have come to experience silence. Young people may see silence as a tool for their social and cultural survival, which could make them even more resistant to change and more unwilling to disclose. Through recognizing how silence permeates through all of the ‘worlds’ described in this paper we can begin to unravel and deconstruct how various people and spaces provide verbal and visual cues to young people about what is acceptable to express and what needs to be kept hidden.
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Chapter 7: Conclusions and Recommendations

Introduction

The findings reported in this dissertation make a contribution to the understanding of psychosocial, ethical, and programmatic aspects of long-term survival with perinatally-acquired HIV infection in the province of British Columbia and abroad. Since the beginning of the HIV epidemic, groups and individuals have worked to give HIV/AIDS a human face, to advocate within their communities, and to support those people both infected and affected by the disease. However, many populations are still socially and economically marginalized making them more vulnerable to HIV-infection and to the sequelae of challenges that arise once an individual receives a positive diagnosis. Although great advances have been made in preventing, treating, and mitigating HIV infection, psychosocial repercussions and program implications for those infected remain under-explored and a low priority. Families and young people living with HIV exist ‘behind the scenes’ in the epidemic and largely without voice or representation in the Canadian context. Indeed, many people who have inquired as to the nature of my work have been surprised to find out that perinatal HIV infection exists in Canada.

This dissertation assembles somewhat dissimilar manuscripts with the intent of providing a glimpse of a much larger process of creating alliances, working with constraints imposed by structural and relational forces, and working collaboratively with multiple and varied stakeholders to effect change in a community. This dissertation describes several processes undertaken to aid in the development of a community-based program for adolescents living with perinatally-acquired HIV in British Columbia.
Summary of Research Findings

The participatory needs assessment described in Chapter 2 marked the beginning of the development of a research partnership that utilized collaborative techniques for collecting data through focus groups and in-depth interviews. The participants in this stage identified gaps in research and areas of program needs. The multiple stakeholders involved in this assessment prioritized areas of stigma, sexual health, and mental health as critical for children as they entered adolescence and adulthood. The results of this study prioritized the views of the young people, drawing on their words to frame the important issues in their lives. It elicited practical program recommendations from providers, caregivers, and the children themselves (n=32) that built a base for the future research and programming activities described in later chapters.

The community-academic partnership that moved the research forward is described in Chapter 3. The results of this partnership are presented in terms of the research stages and processes involved in the development and implementation of the HIV Youth and Child Umbrella Program (HYCUP) Initiative. The purpose of this chapter is to provide an overview of the community-based research process over the course of five years and to document and share the challenges of the partnership process. The HYCUP model presents all the research stages described in this dissertation including conducting the needs assessment, a literature review, an environmental scan, expert interviews and engagement with BC community groups to refine a model and propose a local program/intervention. The processes and challenges are framed by the domains of the technical, the ethical, and the socio-political. The challenges identified included time and resource constraints, differing levels of
commitment and participation, power imbalances between members of the various stakeholder groups, and ethical dilemmas that arise in working with young people such as issues of consent and gatekeeping.

The critical review presented in Chapter 4 examines the body of evidence regarding programming for HIV-positive adolescents. It examines the body of both qualitative and quantitative evidence (n= 46 reports) available to programmers and decision-makers and concludes that few evidence-informed programs are described in the academic literature. Although some program elements such as case management and outreach are emphasized in multiple reports, few commonalities exist and few program ‘core elements’ are adequately evaluated. However, based on the recommendations of the authors, several key facilitators and barriers to programming were extracted. The search revealed a relatively limited body of evidence that presents great challenges in terms of synthesis due to the variability of information provided regarding both programs and their evaluations.

The final two Chapters (5 and 6) are informed by ‘the experts’ (n=15); service providers/interventionists working with HIV-positive adolescents. This study, using qualitative inquiry uncovered key issues that emerge in the programming context. The research examined the core elements perceived necessary for successful programs with populations of HIV-positive adolescents and revealed their role in programming. The core elements discussed by participants were constructed into the ADOLESCENCE planning and evaluation tool that may be used to guide program planners. The elements included ten domains of programming that emerged from the data, thus indicating that programs for HIV-
positive adolescence should be: accessible, context-driven, ethical, collaborative, comprehensive, youth-centered, sustainable, appropriately staffed, youth-friendly, and normalizing. The purpose of the categories and their subcategories is to promote dialogue about programs targeting young HIV-positive women and men and to outline factors to consider for program delivery in various settings and contexts.

The final chapter revisits the issue of stigma in the lives of young people living with HIV, identified in the initial community-based needs assessment as a critical issue to the local BC group. Professional service providers spoke of HIV stigma and stigma management in programming with HIV-positive adolescents. ‘Silence’ emerged as a key theme in the participant narratives, and was embedded in the descriptions of young people’s lives. The silence is conceptualized in various ‘worlds’, the world of the adolescent, the world of the family, and the world of the provider. This chapter illustrates how programmers are aware of the silence that surrounds issues for the young people such as sexual relationships, the ‘family secret’, and sense of self. Silence is a product of oppression and inequity but also a tool for resistance. Silence defends secrets and exists in the spaces, both physical and social, that are created for the young people in order to manage the stigma in their lives. These silences need to be exposed and examined if we are to better understand what the illness truly means to HIV/AIDS- infected young people and how ‘silences’ may minimize or exacerbate their experience of stigma inside and outside the context of programming.
Integrating the Findings

This work integrates multiple and often marginalized fields of research: HIV/AIDS, adolescent health, community-based participatory research, and program planning. In this way it makes a contribution that belongs to no one discipline and no singular body of knowledge. This work therefore has found a comfortable home in the realm of health promotion which is both interdisciplinary and action-based (McQueen, 2001). Green and colleagues (1995) in their study of participatory research in health promotion for the Royal Society of Canada identified four main elements of participatory research for health: community participation, action, education, and research. These elements framed this research and thus will guide the following discussion that integrates the findings with other literature.

Community Participation

The findings of this research highlight the steps that occurred during an ongoing research partnership and provide lessons with potential relevance for others using community-based participatory approaches to research with vulnerable populations of young people. This research presents participatory strategies that engaged various stakeholders to dialogue and plan around how best to address the needs of HIV-positive young people in the BC context of clinical and community service provision. These included involving the young people themselves and their families in identifying their own needs and solutions, conducting research in partnership, creating iterative feedback (hermeneutic) cycles, and working closely with clinicians and representatives from local HIV community agencies to create a health promotion program model for implementation. These strategies are consistent with
community-based participatory research (CBPR) practices described by other authors that advocate for the: identification of common goals and objectives; conducting community assessments; the involvement of community members in research activities; the presence of community organizers; and co-learning processes (Altman, 1995; Israel et al., 1998). By involving the various actors in the process, this research benefited from what Mantoura et al. (2007) refer to as the innovation that results from the “local production of public health” through multi-sectoral, multi-level and multidisciplinary networks.

Also, consistent with findings of other researchers (Israel et al., 1998; Lantz et al., 2005), challenges occurred throughout the participatory process concerning time demands, power differentials between stakeholders, and the question of who represents the community. Population specific participation challenges also arose due to the fact that the target population consisted of minors who have their vulnerability compounded by their lack of personhood and citizen rights. This can be better understood in relation to theories of childhood and the perception of children as incomplete adults (James et al., 2005) and the policies that limit their participation such as requirements for parental consent. Ethical dilemmas associated with conducting research with children are much debated in the literature (Christensen & Prout, 2002; Kay et al., 2003; Doherty & Sandelowski, 1999; Punch, 2002; Walker, 2002) and continue to challenge attempts to meaningfully involve young people in academic-community partnerships to promote adolescent health.

**Action**

The chapters in this dissertation interact to create a community-based research story that integrates action into the process and as the main objective. Consistent with the key
principles of CBPR (Israel et al., 1998), this research included tangible outcomes for communities such as skill-building, financial incentives, authorship, and recognition for agencies/institutions. Smaller action cycles are evident in the continued interactions and knowledge sharing between the various research partners. For example, capacity building with community members was achieved through: offering a facilitation workshop to members; building research capacity in the community; and developing the Community Advisory Board; thus creating smaller-scale changes in knowledge through action. The results presented in the various chapters support reflexive practice by researchers and professionals involved in health and social service provision through critical and conscientious appraisal of what aspects of services are effective and ineffective for young people living with perinatally-acquired HIV in BC.

As the purpose statement of this dissertation includes combining program development with collaborative processes of inquiry and action, all the stages of the research described in this dissertation lead towards implementation of a collectively-proposed research-supported program in the community (Appendix E). As a result of the research, community stakeholders were eager to move forward with a new psychosocial community program for HIV-infected and HIV-affected adolescents in BC. The proposed program was based on the various research stages of the HYCUP initiative resulting in a model of individualized support through case-management services and youth-friendly group activities, recreation, education, and support through a yearly peer-led youth skills symposium. Both case management and peer-based programs are consistent with strategies that have been implemented with populations of HIV-positive and at-risk youth throughout
the United States (Huba & Melchoir, 1998; Rosenfeld et al., 2000). The collaborative planning process used in the partnership also strengthens the potential that the action will be maintained since broad-based community support and participatory planning and implementation of community health programs increases the likelihood of program sustainability (Altman, 1995).

**Education**

Education is a fundamental component of community-based participatory research strategies that differs from more conventional forms of health research (Altman, 1995; Israel et al., 1998). In this work, education was conceived as the process of co-learning and co-construction of knowledge that occurred between the various partners and at each stage of the research. One of the benefits of using community-based partnership approaches is the ongoing interaction and knowledge sharing between academics and partners (Israel et al., 1998; Lantz et al., 2005). As little is known about adolescents living with perinatally-acquired HIV both globally and in the Canadian context, the manuscripts that make up this dissertation have a crucial role in raising awareness about the issues affecting this population of young people in B.C., especially as they pertain to program development and delivery. Findings from HYCUP have been disseminated widely through informal means such as meetings with local HIV and health service professionals and formally through national and international conferences.

Increasingly, those of us in public health and health promotion are being called upon to ensure that research be applicable and ‘translated’ back to participants and communities (CHSRF, 2009; CIHR, 2009). The research contained in this dissertation included multiple
means of information dissemination to reach the various audiences, recognizing that impact was more likely with diverse information-sharing strategies (Currie et al., 2005). It combines with the ‘action’ component to build the capacity of researchers and community-members alike through training opportunities. This research supports the notion that partnerships facilitate the dissemination of research findings and research capacity into the community while creating applied knowledge for researchers regarding feasible research designs and health and social services operation (Currie et al., 2005).

**Research**

The chapters of this dissertation demonstrate how research can contribute to community program planning for health by enhancing the empirical evidence base and documenting processes, people work, and challenges. This research joins calls for comprehensive program models for HIV-positive adolescents (Flicker et al., 2005; Woods et al, 2000) and for strategies to address structural barriers such as poverty and stigma (Abadia-Barerro et al., 2006; DeMatteo et al., 2002). It describes multiple research steps taken as part of the HYCUP project including a needs assessment, literature review, professional perspectives, and social theory, therefore creating various forms of knowledge. This is consistent with research-based planning models proposed in Health Promotion and other fields of research (Green & Kreuter, 2005; Sork, 2000; Raeburn & Rootman, 1998). The qualitative and participatory methodology that framed the research remained flexible and respondent to the needs of the young people, the other stakeholders, and the challenges that arose during the process.

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26 Flexibility is recommended by Israel and colleagues (1998) in response to the methodological challenges of community-based research.
This dissertation presents qualitative research findings. Qualitative research is ideal for bringing forward voices and experience and for understanding contextual issues that influence health and social services for this population. As others have suggested, young people are the best source of information about themselves (Walker, 2002) and as Rich and Ginsberg (1999) state: “qualitative research is an ideal approach to elucidate how a multitude of factors such as individual experience, peer influence, culture, or belief interact to form people’s perspectives and guide their behavior” (p. 372). For this reason, this research begins with involving a group of young people in determining their needs and devising action strategies. This dissertation also brings the voices of international professionals who work directly with HIV-positive adolescents to the forefront, identifying key elements for successful programming and elucidating their understanding of the experience of their adolescent clients.

The various chapters when considered as a whole highlight some key cross-cutting findings. First, is the status of these young people as a ‘hidden’, vulnerable, and disempowered group even within the field of HIV. Second, the impact of HIV stigma on the lives of the BC population of young people with perinatally-acquired HIV (Chapter 2) as well as other similar populations (Chapters 5 and 6) is significant and requires urgent attention in public health initiatives. “Normalization” emerges from this research as not only an adaptive coping mechanism for childhood chronic illness (Rehm & Frank, 2000) but as a programmatic strategy that can potentially minimize or exacerbate stigma (i.e., through reinforcing silence). Third, young people living with HIV are disadvantaged by the structural barriers that face minors in terms of rights to participation in health research and service
provision, despite documents such as the UN Convention of the Right of the Child that assert these rights. The findings of this research are shaped by power that is embedded in existing social and structural systems (Foucault, 1978) including the family, health and social services and research institutions. This dissertation calls for more partnerships between young people and adults in research and services to ensure not only their protection from harm but their meaningful participation in research and programming decisions that affect their health. This is consistent with other researchers such as Ayres and colleagues (2006) who advocate a child rights approach be adopted in the HIV field.

**Contributions and Limitations**

Although this research focuses on a specific Canadian provincial cohort of HIV-positive adolescents, it makes a valuable contribution to the field through presenting an academic-community partnership and describing challenges and lessons, all of which are potentially transferable and useful to other practitioners. Given the similarities between countries like Canada and other resource-rich countries in terms of HIV healthcare service delivery and HIV treatment availability and standards, the research compiled in this dissertation can assist other practitioners in Canada and abroad who are struggling to begin, enhance, or evaluate their programs for young people with perinatally-acquired HIV. This dissertation provides a rich and detailed case study of program development for this vulnerable population of young people, as well as evidence-informed recommendations to strengthen services. It calls for more reflective and participatory practices in service planning and delivery. The major contribution of this work however is its value in the local BC community in terms of building and strengthening partnerships, facilitating shared direction.
for action, and creating research to support future efforts to obtain funding and develop programs for young people with perinatally-acquired HIV in the province (Appendix E).

As a qualitative research project, the results presented throughout this dissertation, are not generalizable and are context specific. The HIV-positive young people, their family members/guardians and their service providers who participated in the initial needs assessment (Chapter 2) are not representative of all these stakeholders elsewhere in Canada and abroad and their priorities and concerns are not universal. Likewise, the professional perspectives that informed the final two empirical chapters (Chapters 5 and 6), cannot be said to represent all people holding similar positions (service providers/interventionists) elsewhere. However, the professionals perspectives were consistent with much of the literature reviewed in Chapter 4, providing a type of triangulation of data. The final categories represented in the ADOLESCENCE tool are quite broad in order to provide a framework that could be flexible enough to apply and adapt to other contexts and various types of programs.

Another limitation of the research process is that the young people themselves were only directly involved in the research in its initial stages. Ideally, with a community-based participatory research strategy, the target populations are engaged and involved in every stage of the research (Israel et al., 1998). However, this was hindered by four main challenges. Firstly, the participation of the young people was constrained by the large amount of time and resources needed to access them and gain outside approval through their ‘gatekeeping’ individuals and institutions. Second, their participation was limited by the
practical problems involved in creating additional developmentally-appropriate research environments and materials. Third, their participation was limited by the unfortunate reality that they do not play a major role in decision-making about the health and social services that they receive. Finally, their participation was constrained by the power differentials between the various stakeholders and ethical concerns of the adult participants regarding the vulnerability of their clients, especially in the context of group discussions and decision-making.

Research Recommendations

Research addressing the needs of the emerging cohort of HIV-positive adolescents who are long-term survivors of HIV is relatively scarce. However, in the past 5 years, we have seen a growing number of publications addressing several pertinent issues for this population including reproductive intentions and pregnancy (Brogly et al., 2007; Ezeanolue et al., 2006), and psychosocial issues (Ayres et al., 2006; Fernet et al., 2007). These studies have been largely qualitative in nature, likely due to the relatively small numbers of long-term survivors globally. Additional research, both quantitative and qualitative, is needed to capture the impacts of HIV on the lives of these young people. A few key areas of needed research identified in the various chapters of this dissertation are included below.

Families with HIV

Family is an important consideration when working with adolescents, whether these relationships are positive, dysfunctional or estranged. In this dissertation family members/guardians of HIV-positive adolescents were represented in several ways. They
added their insight and permitted (through their parent/guardian consent) the participation of young people in the needs assessment (Chapter 2). Also, the reports presented in Chapter 4 included interventions/programs for young people and their family members. Likewise, the international professionals (Chapters 5 and 6) identified family members as potential collaborators in programming for HIV-positive adolescents.

As developing young people, adolescents living with perinatally-acquired HIV are located within complex family systems, often complicated by inequities such as poverty and orphanhood (Dematteo et al., 2002). Families are often disadvantaged and have little power to self-advocate or have a voice in decision-making, including through research avenues. Little is known about the lived experience of families affected by HIV in Canada or abroad, especially those that include adolescent long-term survivors of HIV infection. Research is needed to understand the family context, including potential family impacts on HIV-positive young peoples’ risk behaviours, positive youth development, and HIV transmission rates. Siblings of HIV-positive children and adolescents have been largely ignored in research thus far and constitute an important but poorly understood population. Finally, to date research has focused largely on risk behaviours of adolescents living with HIV rather than their resilience\(^\text{27}\). Research addressing resilience in HIV-positive adolescents and their families may provide more valuable information for practical application in programs and policies.

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\(^{27}\) Masten and colleagues (1990) refer to resilience as a key concept of child development literature and “the process of, capacity for, or outcome of successful adaptation despite challenging or threatening circumstances.” It is conceptualized both as an individual and social construct and may be influenced by “protective” factors such as good parenting, and positive school experiences. Resilience relates to: good outcomes despite high risk, sustained competence when threatened, and recovery from trauma (Masten et al., 1990). The concept of resilience also permits a shift away from a singular focus on the potentially disempowering and problematizing discourse of child and adolescent “vulnerability” or “risk”.
Transitions

As young people mature and acquire more independence from their families, developmental issues around sexuality and transitioning in and out of pediatric and adolescent health and social services need to be better understood for this population of perinatally-infected young people specifically (and chronically ill children generally). More research into legal issues is needed to understand the impact of legislation on the minor population in terms of HIV transmission. Research could examine the criminalization of HIV, how this is communicated to young people living with HIV, how this may positively or negatively impact on risk behaviours and stigma, and where the responsibility lies in the event of HIV-transmission with or without disclosure of HIV status by parents to their adolescents. Transitioning from pediatric and adolescent services to adult services is an area in desperate need of further exploration. Understanding facilitators and barriers to transitioning are essential to ensuring that these adolescents do not “fall through the cracks” (Flicker et al., 2005) as they become adults. This research can be facilitated through the various centres that provide HIV services. Cohorts of children with perinatally-acquired HIV that are followed in pediatric primary care networks worldwide need to continue to be followed into adult services. This would facilitate both quantitative and qualitative studies related to the above issues, in addition to providing valuable surveillance data on morbidity and mortality. Most importantly, these future studies need to actively seek to include the perspectives of the young people themselves and enable their voices to be heard in research and program development.
Stigma

HIV stigma was highlighted as an important issue in the various chapters of this dissertation. Chapter 2 highlighted stigma experiences and the pressing need for programs to address the problem in communities using the BC context. The expert interviews with service providers/interventionists informing Chapters 5 and 6 included the provider-perceived stigma experiences of HIV-positive adolescents and the management of this stigma in the context of service provision. Further research is needed to understand the profound impact that stigma has on the lives of these young people through their own accounts. Practitioners, researchers and policymakers need to better understand what helps and hinders stigma and how HIV-positive young people feel come to feel ‘safe’. Given the results described in Chapter 6 regarding the function of silence in the lives of HIV-positive adolescents, more research is needed to explore HIV disclosure in this population and how different physical and social spaces facilitate “breaking the silence.” The function and practice of “normalization” as it relates to stigma reduction or exacerbation needs to be further explored in order to better inform program practice. The “courtesy” stigma (Bogart et al., 2008) experiences of other family members and of those close to HIV-positive adolescents such as their service providers is an area of research that also deserves further exploration.

Interventions

There is very limited research available to inform successful program design with HIV-positive adolescents (as demonstrated in the review presented in Chapter 4). Although

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28 Bogart and colleagues (2008) describe courtesy stigma as the prejudice and discrimination directed at people due to their association with stigmatized individuals. For example, this has been described in detail by authors in relation to HIV-positive parents who fear that their children will suffer discrimination should they disclose their status to community members (Faithfull, 1997; Sandelowski et al., 2004).
the research presented in this dissertation begins to make inroads into the area of HIV programming for this group, much more research is needed to clarify the effectiveness of interventions targeting this population. For example, as others have suggested (Kelly et al., 2000; Ingram et al., 2008), research is needed to address the questions surrounding the replication of successful intervention: what are the ‘core elements’ of a program that are potentially transferrable to other settings; how much can interventions change to suit their new community contexts while staying true to the original successful program design?

However, to date, the definitions of “success” in interventions have been limited to narrow criteria mirroring conventional quantitative epidemiological designs such as the randomized control trial. Qualitative research could make a valuable contribution to these evaluations by illuminating the influences of various contextual elements on success and by providing methodological alternatives for evaluating program effectiveness. In this way, through combining quantitative and qualitative research methodologies, we can begin to understand not only that certain programs are effective but why and how they are effective, for whom they are effective, and what meanings various stakeholders attribute to this effectiveness.

Finally, community-university partnerships need to be further explored for designing, implementing, and evaluating programs. This will help to ensure that community programs are both sustainable and effective. Academic researchers can contribute their expertise and resources to the design and implementation of thorough evaluations while community members and agencies can contribute their local knowledge and can help to ensure that programs are appropriate for communities (Altman, 1995). In the case of HIV-positive adolescents, these types of partnerships are vital to producing effective programs,
meaningfully involving the target population in the research, and building ongoing community supports.

**Program and Policy Recommendations**

Many programmatic recommendations can be found throughout the chapters of this dissertation. For example, the findings from the review of the literature regarding HIV programs for adolescents indicates that we are far from achieving a cohesive body of evidence-informed programs specific to this population of young people. The results of this research provide knowledge for practical application by programmers and policymakers. They suggest that there are pressing needs that are going unmet in the BC population of young people with perinatally-acquired HIV. As the primary researcher on this project, I have been immersed in the field of pediatric HIV and community HIV programming for over six years. I have thus been able to integrate knowledge from multiple sources in order to reach a complex and sophisticated understanding of the types of programs and policies that may be beneficial to this population. Based on the empirical research presented in this dissertation and my own aggregate knowledge, three key areas are highlighted for program and policy recommendations: support, stigma reduction, and knowledge translation.

**Support**

The findings of this research emphasize the need for more support and education services targeting the emerging population of adolescents and young adults living with perinatally-acquired HIV in BC. Within clinical and community services, adolescents’ unique developmental needs should be addressed directly as well as indirectly within the
context of their family. Family-based models of service delivery, while recognizing the significant impact of family on the health of children and adolescents have potential for occluding the rights and agency of young people when it comes to their role in decision-making in matters that affect them. Adolescent peer-based support programs were discussed and recommended by various stakeholders throughout the course of the study and could be useful in both community and clinical environments.

Due to the small numbers, programs may be integrated into existing services targeting HIV-positive youth and adults. These services need to reach out to those in the younger age ranges of “youth” (i.e. adolescents) including those young people who have been perinatally-infected. Policies can help to support organizations, service providers, and the young clients through creating funding opportunities specific to small subpopulations of high needs adolescents living with HIV and/or chronic illnesses in general. Other support and education program needs of adolescents that are evident from the results include mental health services such as counseling and case management, as well as those that address sexual health needs through education and skill-building around issues such as HIV disclosure to romantic partners. Support services can aim to help mitigate the effects of stigma through working with individuals and families to strengthen coping mechanisms specific to stigma and discrimination. Support and education programs are also needed to help with important transitions in the lives of these young people by facilitating opportunities such as vocational or post-secondary training.
Support programs and policies should work together to maximize the physical, psychosocial and cultural health of the adolescents through working with their guardians, families, service providers, and communities to decrease barriers. Policies need to fight against the structural violence experienced by these young people due to factors such as their status as minors, ethnicity, and poverty. These policies could include poverty alleviation strategies such as government subsidies for HIV-positive adolescents, homecare support for families, low-income housing for emancipated minors and young adults living with HIV. These types of strategies begin to address the various ‘layers’ of stigma (described in Chapter 6) that extend beyond the HIV infection itself to factors that deeply impact on the lived experiences of the young people and those that are close to them.

**HIV Stigma Reduction**

This dissertation highlights several key examples of the impacts of HIV-related stigma on the lives of young people living with HIV, both in the local BC context and from the perspective of members of the international professional community. As other authors have noted, stigma may prevent people living with HIV from accessing treatment and support services (Chesney & Smith, 1999; Herek 1999; Rao et al., 2007; Vanable et al., 2006). Stigma reduction efforts can be multi-leveled (statutory, policy, programs) and may come in the form of information-based approaches, skills-building, counseling, and contact with affected groups (Brown et al., 2003; Heijnders & Van Der Meij, 2006).

Specific health promoting educational campaigns and policies are needed to sensitize both the public and professionals about the damaging impact of HIV stigma. Responsible public awareness media campaigns such as those initiated by Health Canada and the BC
Persons with AIDS Society, need wider and more consistent implementation and evaluation. Popular television programs for young people could introduce an HIV-positive character with the goal of exposing young people to HIV-related issues and facilitating more empathetic and educated responses to HIV in communities. Educational materials that exist for children including books like “Come Sit by Me” (Merrifield, 1990) and “The Gathering Tree” (Loyie & Brissenden, 2005) could be incorporated into school curriculums and promoted to parents to increase awareness and acceptance in future generations of young people and adults. These practices of benevolent ‘contact’ and education have been found to be effective at reducing stigma (Brown et al., 2003; Heijnders & Van Der Meij, 2006) and should be promoted and continued. Educational campaigns should also target professionals with anti-oppressive non-stigmatizing education. For example, this could involve increasing the HIV awareness of students training to become teachers, nurses, and physicians through skill-building workshops or educational packages (e.g., including DVDs, reading materials, and classroom resources).

HIV needs to be mainstreamed through various services targeting young people such as youth clinics, recreational programs, social services, so that people who work in these organizations are both aware and equipped to work with HIV-infected young people and to ensure that policies are in place to protect these young people and their families should any discrimination occur. School boards and universities for example could examine their sexual education curriculums to ensure that information is not fear-based but rather provides accurate and non-stigmatizing information. These institutions also need clear policies and

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29 This strategy was employed in Degrassi Junior High (a pioneering popular Canadian series in the 1980s).
procedures for accommodating the needs of HIV-positive young people and providing confidential services. For example, they might engage a professional school liaison whose role it is to mediate between HIV community and clinical services and guide the young people through the administrative details and facilitate access to any required special services. Finally, health services that work specifically with HIV-positive children and adolescents need to develop clear policies that use a child rights-based and developmental approach. For example, these could establish the maximum age by which disclosure of HIV must occur from parent to child, after which health professionals are mandated to disclose the information to their young patients.

**Knowledge Translation**

Knowledge translation or “KT” has quickly become a part of the Canadian health research rhetoric over the past decade. The Canadian Institutes of Health Research (CIHR) defines knowledge translation as a “dynamic and iterative process that includes synthesis, dissemination, exchange, and ethically-sound application of knowledge to improve the health of Canadians, provide more effective health services and products and strengthen the health care system” (CIHR, 2009). A key feature of the research detailed in this dissertation and the general goal of the HYCUP Initiative was the commitment to creating open channels of communication and ongoing dialogue with research participants, community agencies, and project partners throughout the course of the research.

Recommendations for knowledge translation are based on the findings that few resources exist to inform programming for adolescents living with HIV. Available evidence describing programs lacks pertinent descriptions and is difficult to synthesize due to
variability in reporting. In the academic literature, publishers may need to change their authorship guidelines for intervention/programmatic articles (e.g., longer word lengths and headings) in order to facilitate the transfer of knowledge to and from communities. Although programs exist, this knowledge is often kept within the organizations. Programs that spring from academic-community partnerships are needed to begin to address this gap through the production of evaluations and through dissemination. Programmers need to include continuous documentation of what works and what does not work and create policies around sharing local knowledge with formal and informal networks of providers and researchers in their communities. Resources produced from research partnerships and community-based initiatives need to be adolescent friendly and tailored to the community. For example, resources for street-entrenched youth that use profane language may need to be altered to suit younger adolescent audiences and the guardians/parents who will be consenting to their participation in a given program.

Knowledge translation involving the adolescents themselves in the process is paramount to conveying both the most effective messages and empowering young people. Organizational policies at universities and community agencies that commit to meaningfully engaging young people in program design and evaluation will assist in strengthening the impact of the research on program delivery. Researchers also need to be encouraged to work with minors and to conduct community-based participatory research. CBPR policy recommendations have received thorough attention by other authors (Israel et al., 2001). Researcher training programs may include for example: skill-building around ethically partnering with community-based organizations and the young people they serve; youth-
friendly research strategies; and incentives/resources to manage the extra administrative burden of working with minors (e.g., parental consent) or community agencies (e.g., developing Memorandums of Understanding, contracts, etc).

Concluding Remarks

Although HIV-affected families and adolescents living with perinatally-acquired HIV represent a small and dispersed population in the Canadian context, they are faced with extremely complex challenges, health service needs, and health inequities. Lessons learned in resource-rich settings such as BC, where available treatments and medical care has prolonged the lives of HIV-infected children may be extremely valuable in helping other countries as their access to HAART improves and children’s survival lengthens. The processes involved in planning research and programs with these populations may also be transferrable to other areas of childhood chronic illness that may have similar limitations due to small, decentralized populations, with high healthcare needs and increasing lifespan.

As Linda Richter (2008), the Director of Child, Youth, Family, and Social Development for the Human Science Research Council in South Africa stated in her keynote address during the 2008 International AIDS Conference30

...children have simply been too small to count, too minor to matter. There is a lack of good data on children, especially between the period when mother-to-child transmission occurs and the time of adolescent risk of infection, where we are now learning of higher than expected prevalence rates.

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30 This was the first plenary presentation on HIV affected and infected children at the International AIDS Conference since its inception 23 years ago (Richter, 2008).
If we are going to continue to see decreases in the health inequities in the field of HIV in terms of resource allocation, structural violence, and system changes, we need a better understanding of those populations within the epidemic who continue to go under-represented and without voice. There is a clear need for more research about adolescents with perinatally-acquired HIV and the diverse and rich contextual factors that shape the experience of their illness. Case studies of program development and practice need to be shared and health promotion programs and services need to begin to target the needs of this population of HIV-positive young people. The findings of this research address some of the gaps in the literature by examining one group of adolescents living with HIV in BC and working with multiple stakeholders towards addressing unmet needs through community-based participatory research and programming.
References


Appendix A: Institutional Review Board Certificate of Approval
Certificate of Approval

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<td>Paediatrics</td>
<td>B03-0242</td>
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INSTITUTIONS WHERE RESEARCH WILL BE CARRIED OUT:
Children's & Women's Health Ctr.

CO-INVESTIGATORS:
Alimenti, Ariane, Paediatrics; Burdge, David, Medicine; Chapman, Gwenneth, Food Science; Fielden, Sarah, Health Promotion Research; Frankish, James, Health Promotion Research; Scheckter, Lori.

SPONSORING AGENCIES

TITLE:
How Do Older Children with Perinatally-Acquired HIV “Live Positively” within Their Larger Healthcare Community

APPROVAL DATE: JUL 1 0 2003

TERM (YEARS): 1

DOCUMENTS INCLUDED IN THIS APPROVAL:

CERTIFICATION:
The protocol describing the above-named project has been reviewed by the Committee and the experimental procedures were found to be acceptable on ethical grounds for research involving human subjects.

Approval of the Behavioural Research Ethics Board by one of the following:
Dr. James Frankish, Chair,
Dr. Cay Holbrook, Associate Chair,
Dr. Joe Belanger, Associate Chair

This Certificate of Approval is valid for the above term provided there is no change in the experimental procedures
## Certificate of Approval

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<tr>
<td>Compton, Miranda, Social Work &amp; Family Studies; Fielden, Sarah, Health Promotion Research; Hogg, Robert, Health Care/Epidemiology; Wood, Evan, Medicine</td>
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<td>1</td>
<td>Aug. 1, 2006, Contact letter / Consent form / Questionnaires</td>
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**Certification:**

The application for ethical review of the above-named project has been reviewed and the procedures were found to be acceptable on ethical grounds for research involving human subjects.

---

**Approved on behalf of the Behavioural Research Ethics Board**

by one of the following:

- Dr. Peter Suedfeld, Chair
- Dr. Jim Rupert, Associate Chair
- Dr. Arminee Kazanjian, Associate Chair
- Dr. M. Judith Lynam, Associate Chair

This Certificate of Approval is valid for the above term provided there is no change in the experimental procedures.
October 2, 2003

Certificate of Approval

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CO-INVESTIGATORS:
Fielden, Sarah; Scheckter, Lori; Frankish, James; Chapman, Gwenneth

C&W DEPARTMENTS, PATIENT BASED PROGRAMS AND ADMINISTRATIVE JURISDICTIONS IMPACTED BY THIS STUDY:
Specialized Women’s Health

SPONSORING AGENCIES:
Unfunded

TITLE:
How do older children with perinatally-acquired HIV “live positively” within their larger healthcare community?

APPROVAL DATE
October 2, 2003

TERM OF APPROVAL
October 2, 2003 - July 9, 2004

CERTIFICATION:

The protocol for the above-named project have been reviewed by the Research Review Committee and has been found to be appropriate with respect to ethics, methodology, patient impact and availability of C&W resources

[Signature]
Dr. M. Levine, Interim Chair

This Certificate of Approval is valid for the above term provided there is no change in the research protocol
Appendix B: Needs Assessment Community Report (Adult)
Exploring the Needs of Older Children with Perinatally-Acquired HIV in British Columbia

Research Report, 2005

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Executive Summary

“It’s not like you have a third eye or something... I can hug you, I can kiss you; you’re not going to get it. People think that way. They’re just way too paranoid and way too sketchy about everything. I don’t think that people need to be educated in the way of what AIDS and HIV is, because obviously people know what it is; they need to know how people are with it.”

(HIV-Positive Teen)

This Report:
This report summarizes the findings of a study conducted in 2003-2004 which examined the needs of older children with perinatally-acquired HIV in British Columbia (BC). It describes and interprets the ideas and experiences of a number of older children with perinatally-acquired HIV, their caregivers, and their service providers. It is meant to be used by participants and other interested parties (e.g., healthcare professionals, educators, non-governmental representatives, HIV-affected families) to give voice to participants, inform stakeholders, and be a tool for positive change.

Background and Design:
Many children with perinatally-acquired HIV in BC are approaching and reaching adolescence. As these children grow up, their needs are evolving and additional programs and services may help to encourage their optimal development. The study outlined in this report sought to identify the needs of older children with perinatally-acquired HIV in BC, to describe the positive influences in these children's lives, and to suggest strategies to address the various needs. It used a community-based participatory action research approach, drawing data from four focus groups and seven in-depth interviews representing various stakeholders involved with the Oak Tree Clinic in Vancouver. Focus groups and interview participants included 10 children over eight years old with perinatally-acquired HIV, six of their familial caregivers, five of their foster parents, and eleven of their service providers. Analysis was done collaboratively and qualitatively during the focus groups, by pooling the group and interview responses together, and by coding the transcripts. Participants were asked to consider and discuss what was going well in the lives of the older HIV-positive children, what issues they face, and what could be done to make the children’s lives better.

Positive Influences:
Participants identified family and peer support, community agencies, advances in medical therapy, and effective multidisciplinary care as positive forces in the children's lives. These resources are currently helping to meet the needs of the HIV-infected children and their families.

Thematic Framework:
The key interconnected themes identified by participants were located along a spectrum of socio-cultural to psycho-medical issues relevant to the health and wellbeing of the older HIV-positive children. They included:
- Social Stigma as it relates to fear, secrecy, trust, disclosure, isolation and knowledge in the children’s lives.
• **Poverty** and its impact on family security, necessities, and activities for the children.
• **Cultural identity** and its importance for the children in foster care and from Aboriginal families.
• **School** and issues of socialization, discrimination, infection control, and support services impacting on the children.
• **Family issues** including stresses, dynamics between children and caregivers, and the support and education of the HIV-positive children.
• **Peer relationships** and the potentially supportive and detrimental roles that peers play in these children’s lives.
• **Recreation** and its importance for the children’s socializing, physical health, and self-esteem.
• **Sexual Health** as it relates to promoting positive sexuality, preventing transmission, and future intimate relationships.
• **Mental Health** as it relates to bereavement, anxiety, permanency, disclosure, stability, self-esteem, identity, and feeling “normal”.
• **Nutrition** and getting the right nutrients, access to food, and social aspects.
• **Medications** and concerns about adherence and social events.
• **Multiple Diagnoses** and the additional issues that arise for the children and their families.
• **Physical Health** and wanting to keep the children as healthy as possible.

**What can be done?**
Participants identified strategies for future program development which could further meet the diverse needs of this group and focus in on some shared issues and unmet psychosocial needs of the children in areas of **sexual health, mental health, and stigma**. The strategies could be categorized into 5 areas: peer-based programs for the children, professional services, support programs for families, educational programs for communities, and research.

**Examples of Strategies**
- Facilitated Youth group or E-group
- Youth Drop-in Centre
- Buddy/mentorship programs for families and children
- Public education sessions to reduce stigma
- Outreach mental health worker

**Conclusions:**
The needs and actions identified suggest emphasizing services that are age-appropriate, family-centered, and which bring the HIV-infected children together with each other for support. This study has several implications for future program planning, research, and education.
Acknowledgments

I would like to acknowledge and give thanks to the many children, families, and service providers who shared their time and experiences as part of the research process. It is my great honour to have worked with the participants and been permitted to document some of the realities that exist for HIV-infected children.

This research was supported through studentships and included awards from the Michael Smith Foundation for Health Research, the Western Regional Training Centre for Health Services Research, and the Partners in Community Health Research Training Program.

I would also like to acknowledge the co-investigators on this study:

Oak Tree Clinic:
Lori Sheckter
Ariane Alimenti
Jack Forbes
David Burdge

University of British Columbia:
Jim Frankish
Gwen Chapman
Samuel Sheps
Susan Cadell

Sincerely,

Sarah Fielden
1. Introduction
Approximately 58,000 HIV infections have been reported in Canada since 1985. Among these, 464 confirmed cases of HIV have been in children, according to a recent Canadian surveillance study of live infants born to identified HIV-infected mothers (Health Canada 2005). In resource rich countries such as Canada, pediatric HIV infection is now recognized as a chronic childhood illness that presents patients and families with challenges and stresses including varied service needs (Brady, Crim, Caldwell, & Koranyi, 1996). Studies indicate that the issues for HIV-affected families are diverse and complex and can include family illness, death of parents, orphaned children, parental addictions, poverty, isolation, lack of emotional support, stigma and family secrecy (Antle et al., 2001; Bor, 1990; DeMatteo et al., 2002).

With the advent of combination antiretroviral therapies in the mid-1990s, children born with HIV are living healthier, longer lives. There is a group of approximately 35 children with perinatally-acquired HIV in British Columbia ranging from young children to teenagers (Alimenti et al., 2003). Many of these children are approaching or have reached adolescence. This brings new challenges for HIV-infected children and youth, their families and their healthcare and community service providers. Since these children represent a newly emerging group of youth in the HIV epidemic, there is little accessible information on their life experiences thus far.

2. Purpose and Objectives
The purpose of the study was to find out what can be done to further meet the needs of older children in BC growing up HIV-infected. It sought to work collectively with older HIV-infected children, their families, and their service providers to assess the needs and develop strategies for action - to lay the foundation for future health promotion interventions with this population of children and youth.

The objectives of the study were:
• To identify what was going well for these HIV-infected children
• To identify and categorize the children’s needs
• To identify and prioritize action strategies that could address some of the needs of these children

3. Research Approach and Methods
A community-based participatory research project seemed appropriate to explore what areas need emphasis in future programming and to give participants a voice in the study. Participants included older HIV-infected children in BC, foster and familial caregivers and healthcare and community service providers. Qualitative inquiry and research techniques were used to capture and analyze the stories and experiences of participants. Close attention was paid to issues of ethics and confidentiality throughout the research process.
3.1 Participants
In 2003 and 2004, a total of twenty-four stakeholders, selected by Oak Tree Clinic staff, agreed to participate in the focus groups and eight participants in the interviews. The four focus groups were divided based on similar characteristics of the participants: eight HIV-infected children between nine and sixteen years old, three familial caregivers, five foster parents, and eight healthcare and community service providers. The interviews involved an additional two children, three familial caregivers, and three healthcare professionals. All the children selected were born with HIV and had lived in BC for the majority of their lives. In order to be selected, the affected families and service providers had to have had experience with one or more of these children. The distinct participant groups were chosen to encourage open dialogue between peers during the focus groups and to get a cross-section of perspectives from people with different types of influence in the children’s lives. The group as a whole represented the “community of interest” chosen as the target for the research, having the shared purpose of ensuring the welfare of these HIV-positive young people.

The children who participated in the study represented a sample of the larger population of children who met the study criteria of being an older child (over eight years of age) having perinatally-acquired HIV, and growing up primarily in British Columbia. Figure 1 shows select characteristics of the sample of children who participated in the study and those in the slightly larger population as a whole at the time the research took place. The sample differs slightly from the larger group, with an over-representation of children from ethnic minorities and those in foster care. All 18 children and their family members were asked to participate in the study. Out of these, 10 children and 11 family members agreed to take part, representing a total of 13 BC families. The children and family members who chose not to participate tended to live further away from Vancouver and many were either not ready or not willing to talk about HIV and potentially “out themselves” to other people in the community. Service providers were selected purposively to include various disciplinary perspectives and agency representatives. Two were unable to participate due to scheduling difficulties.
The caregivers were divided into two groups: familial and foster caregivers. The familial caregivers included biological family members ranging in age and relationship to the children. There were three men and three women in this group; four of them were the sole primary caregiver, while two of them were married to each other. The foster parents had varying years of experience fostering the HIV-infected children, ranging from two to 15 years. There were two women and three men in this group with two being a married couple. These families lived at various distances from Vancouver, from a 10-minute to 3-hour commute by car.

Service providers included healthcare professionals from various disciplines including medicine, nursing, social work, and other allied professions. Community service providers included representatives from the Positive Women’s Network, Hummingbird Kid’s Society, Camp Moomba, and the Ministry for Child and Family Development. There were two men and 9 women in this group and their experience working with the HIV-positive children ranged from a few months to 14 years. Some knew all of the children in the population while others had worked with only one or two.

### 3.2 Data Collection and Analysis

A series of four 3-hour focus groups and seven in-depth interviews were held between October 2003 and February 2004 as part of the research project. The focus groups were conducted using a workshop format with a series of questions designed to identify needs and develop some suggestions and strategies for action. The interviews were a second cycle in the research and followed a similar format. Interview participants were

**Figure 1: CHARACTERISTICS OF CHILDREN SAMPLE VS POPULATION**

<table>
<thead>
<tr>
<th></th>
<th>SAMPLE* N = 10</th>
<th>POPULATION* N = 18</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Gender</strong></td>
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<td></td>
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<tr>
<td>Male</td>
<td>5 (50%)</td>
<td>10 (56%)</td>
</tr>
<tr>
<td>Female</td>
<td>5 (50%)</td>
<td>8 (44%)</td>
</tr>
<tr>
<td><strong>Age</strong></td>
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<td></td>
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<tr>
<td>9-10</td>
<td>4 (40%)</td>
<td>7 (39%)</td>
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<td>11-12</td>
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</tr>
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<td>13-16</td>
<td>3 (30%)</td>
<td>5 (28%)</td>
</tr>
<tr>
<td><strong>Ethnicity</strong></td>
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<td></td>
</tr>
<tr>
<td>Caucasian</td>
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<td>7 (39%)</td>
</tr>
<tr>
<td>Child of Colour</td>
<td>3 (30%)</td>
<td>4 (22%)</td>
</tr>
<tr>
<td>Aboriginal</td>
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<td>7 (39%)</td>
</tr>
<tr>
<td><strong>Caregiver</strong></td>
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<td></td>
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<tr>
<td>Two Biological Parents</td>
<td>0 (0%)</td>
<td>0 (0%)</td>
</tr>
<tr>
<td>Foster Parent(s)</td>
<td>5 (50%)</td>
<td>9 (50%)</td>
</tr>
<tr>
<td>Biological Parent</td>
<td>3 (30%)</td>
<td>6 (33%)</td>
</tr>
<tr>
<td>Sibling or Grandparents</td>
<td>2 (20%)</td>
<td>3 (17%)</td>
</tr>
<tr>
<td><strong>Treatment</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>On Antiretroviral Therapy</td>
<td>7 (70%)</td>
<td>15 (83%)</td>
</tr>
<tr>
<td>Elective Treatment Interruption</td>
<td>3 (30%)</td>
<td>3 (17%)</td>
</tr>
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<td><strong>Attends School</strong></td>
<td></td>
<td></td>
</tr>
<tr>
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<td>10 (100%)</td>
<td>18 (100%)</td>
</tr>
<tr>
<td>No</td>
<td>0 (0%)</td>
<td>0 (0%)</td>
</tr>
<tr>
<td><strong>School/Behavioural Difficulties</strong></td>
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<tr>
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<td>7 (70%)</td>
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</tr>
<tr>
<td>No</td>
<td>3 (30%)</td>
<td>7 (39%)</td>
</tr>
<tr>
<td><strong>Attends Summer Camp</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>10 (100%)</td>
<td>14 (76%)</td>
</tr>
<tr>
<td>No</td>
<td>0 (0%)</td>
<td>4 (22%)</td>
</tr>
</tbody>
</table>

* Includes percentage of totals within group at time of study

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**Focus Group Facilitators:**
- Sarah Fielden (M.Sc. Student, UBC)
- Lori Shecter (M.S.W., Clinical Social Worker, Oak Tree Clinic)

**Interviewer:**
- Sarah Fielden
selected specifically when they were unable to attend focus groups and when it was believed they would provide additional insight and elaborate on certain issues which emerged from the focus groups. The interviews supplemented the focus group data and were conducted in participants’ homes (family members) or the office (healthcare providers). Each focus group and interview addressed similar questions based on the objectives of the study in order to be able to pool the results for analysis. Collage was used during the children’s group to allow creative expression of their ideas and as a vehicle for discussion. Focus groups were sequenced intentionally to build on children’s ideas with the children’s focus group held first, followed by the familial caregiver group, foster parent group, and service provider group. The analysis was done collaboratively in each focus group by grouping issues under thematic headings and then the responses were pooled together by the primary researcher (author of this report) to create the main themes. Each of the focus group transcripts was then labeled and indexed to verify the themes and to draw out sub-categories and examples using people’s own words. Interview transcripts underwent similar analysis with the use of NVivo qualitative software. The results are meant to reflect the descriptions and interpretations of participants as well as the interpretations of the primary researcher.

3.3 Participatory Approach
The study was designed to use a community-based participatory action approach. This approach is increasingly popular in health research and has been used extensively in the field of HIV care. Community-based participatory research is seen to be a respectful method of conducting research and is meant to involve representatives from the participant groups in various stages of research (i.e., not just as passive research subjects). This is also reported to increase the quality and utility of results. To this end, some of the participants in this study were asked to review and revise the proposed research plan before the focus groups and interviews occurred and to debrief after the sessions with the researchers/ facilitators. The format of the discussion questions was open-ended, flexible, and non-directive – allowing participants to emphasize what they found to be most important and wanted to discuss. Six participants took part in a half-day facilitator training workshop in order to assist with the running of the focus groups. All participants were invited to take part in the data analysis and dissemination of the findings and to contact the researchers with any additional feedback or questions. In March of 2004, two of the study participants joined the researchers to participate in a national conference on children, youth, and families affected by HIV. During the first half of 2005, a preliminary report of study findings was sent to all participants for their review. Eight participants (2 foster parents, 2 familial caregivers, and 4 healthcare providers) and an Oak Tree Clinic Director reviewed this document and provided additional feedback which was then incorporated into the final report.

3.4 Ethics and Confidentiality
Ethical approval for the study was granted by the Behavioural Research Ethics Board at the University of British Columbia and the Research Review Committee at the Children’s and Women’s Health Centre of British Columbia. Informed consent was obtained from adult participants. Parental/guardian consent and verbal assent were obtained for all the children involved in the study. Information in the focus groups was shared amongst those attending the focus groups and with the two facilitators. Data from the interviews was shared with the interviewer and, in the case of one couple interviewed, between the spouses. Focus group and
interview tapes and transcripts were accessible to the co-investigators in the study from the Oak Tree Clinic and the University of British Columbia. Focus group participants were asked not to share information regarding other participants’ responses outside of the groups. The quotations contained within this report are anonymous and identifying information such as names, locations, and gender may have been changed to maintain confidentiality.

3.5 How the Process Went?
Through debriefing with five of the participants at the end of the focus groups, the cooperative focus group process was discussed. The mood of the focus groups was said to be excellent, with people being open and honest with one another and engaged with each other throughout the sessions. It was very much led by the participants within a loose structure maintained by the primary researcher. The facilitation was non-directive and was not felt to impede others from freely expressing their ideas. Most of the participants expressed their enjoyment of the sessions and appreciated the opportunity to learn from each other. All of the participants met new people through the process. The children, although many had previously met through a summer camp (Camp Moomba), had never disclosed their HIV-positive status to one another. The focus group therefore provided a unique opportunity for the children to interact for the first time with other children whose HIV-infected status was actually known to them. The participants involved in the debriefing agreed that the process was empowering and community-building, allowing new links to be formed and giving a forum to talk about an issue that few others can relate to.

4. Research Findings
The results of the study described in the following sections illustrate the diversity and complexity of the issues which affect the lives of HIV-infected children and their families. The context of care outlined below highlights the services and the larger system that the children, families, and providers operate within. Other sections describe participants’ responses to questions regarding the term “living positive” and the enriching aspects of the children’s lives. Another section gives special emphasis to responses, methods, and interpretations based on what the children said and did during their involvement in the research. The majority of this section on the study results, however, is dedicated to reporting the multitude of needs and issues affecting the children identified through discussions with participants. These are loosely subdivided into three main areas: sociocultural, psychosocial, and psychomedical. Each major issue described within is accompanied by a brief italicized summary at the beginning to synthesize the information that then follows. The Research Findings section goes on to describe issues of future planning and action strategies identified through the focus groups and interviews as well as additional strategies for action and recommendations for future interventions identified by the primary researcher.

4.1 Context of Care
The network of services available to these children is represented in Figure 2.
These organizations and agencies work together to meet the needs of the children and their families. Professional health services include the multidisciplinary team at the Oak Tree Clinic and the children’s General Practitioners (GPs). Children visit the Oak Tree Clinic generally every three months and receive specialized medical treatment from nurses, pediatricians, pharmacists, social workers, and dietitians. There is also a child psychiatrist available for assessments with children as needed. The Oak Tree Clinic staff also liaise with professionals in the community (e.g., social workers, counselors, GPs) who may be providing services to individual children closer to their homes. Community AIDS Service Organizations (ASOs) specifically designed for children, both children who are HIV-infected and those who are HIV-affected (i.e., a family member is HIV-positive), include a yearly summer camp, Camp Moomba, and the Hummingbird Kid’s Society that hosts monthly birthday parties. Other ASOs and community agencies provide services that some children access with their families, such as food provided through AIDS Vancouver, the Positive Women’s Network (PWN) and a Loving Spoonful; housing provided through Wings Housing; and financial assistance provided through the Ministry of Children and Family Development (MCFD). Many of the children have also had a wish granted by Wish Foundations.

4.2 What is “Living Positive”?
When participants from all four groups were asked what they associated with the term “living positive”, people thought of the HIV virus itself and a state of health (being healthy or unhealthy). Participants also mentioned the difficulties for children and families living with HIV such

“When I hear the word living positive... it’s PMA to me, positive mental attitude. It’s about living your life and taking the best you can from whatever you can.”
as stigma, isolation, uncertainty and financial insecurity. The term brought to mind the network of services offered to people with HIV and the need for children with HIV to have the same opportunities as other children. Most of the groups associated “Living Positive” with a positive state of mind and body, and emotions such as happiness, hope, optimism, having fun, and feeling safe.

4.3 What’s Going Well In the Children’s Lives and Why?
These children have many aspects of their lives that are going well including personal characteristics, family, peer interactions and many clinical and community services. Many of the children have seen great improvement in their physical health over the past few years attributed to advances in medical therapy. The medications themselves have improved in terms of palatability and reduced number of pills. Some children are now on a “drug holiday” (treatment interruption) which allows them more freedom. Self-esteem and confidence were cited as personal strengths that helped some of the children cope with their HIV. Many participants mentioned that the children’s family situations were also working in the children’s favour, with a positive family attitude, and positive influences from home surroundings such as supportive and stable home environments. Socially, the support and interaction with friends, taking trips and holidays, and actively being a part of their communities were seen as going well for some of the children. The Oak Tree Clinic and its sensitive, nurturing, and informative multidisciplinary team members were praised in the focus groups and interviews as a very positive force and safe place in the lives of the children and their families. The family-centered health services model of the Oak Tree Clinic was also said to allow for easy transitioning from pediatric to adult care. Participants mentioned community services as a positive force in the children’s lives. Low staff turnover was thought to increase the quality of care provided by these organizations. Some participating healthcare providers reported that the children have considerable resources relative to other children with chronic illnesses.

4.4 What Did the Children Say?
The children all seemed to have a lot of fun during the focus group and enjoyed each other’s company. It was clear, however, that many children in the group were not ready to discuss their HIV in a group setting. Despite this, it could be inferred from the children’s collages and comments that many were showing an interest/curiosity about sexual matters, and that they were largely interested in recreational activities. After the session, some of the older children expressed their desire to learn more about HIV and expressed concerns about their health and future to the focus group facilitators. During the focus group, most of the children enjoyed doing the collages addressing the question “What is good and what is bad in your life?” When children talked about their pictures and their lives, they talked mostly about what they liked to do with friends and family in terms of recreational interests such as skateboarding, music, biking, pets, travel and games. This group of children did not include any mention of HIV or anything considered “bad” as part of their collages. Also, despite the provision of magazines targeted at Aboriginal youth and the large proportion of Aboriginal children, none of the children chose pictures from these resources to include in their collages. When asked what would make their lives better, some of the children talked about wanting a cure for HIV and wanting immortality. The children had unique responses about who could help make their lives better, including God, their parent(s) or caregiver, and themselves.
They also had a lot of ideas about recreational activities they could do together as a group such as rock-climbing, bowling, and movie nights.

To supplement the data from the focus group, additional children were recruited for two interviews. They contributed to the data significantly with their insightful comments and stories. They were able to articulate their concerns regarding issues such as stigma, disclosure, medications, and sexual education. Whereas the ages of those children who participated in the focus group tended to be younger, the children interviewed were already teenagers and seemed better able to think abstractly and reflect on the reality of their HIV-infection.

4.5 Priority Needs
The major needs, issues, concerns, and problems identified by the various groups were complex and included psychomedical, psychosocial and sociocultural issues. Health status varies considerably from one child to another and for the same child over time, corresponding to their varying levels of need. The discussions in the familial caregivers group focused largely on the issues of stigma, school, medications, nutrition, and sexual health. While the foster parents also emphasized nutrition and stigma, they focused more on medical issues such as medication side-effects and also cultural and natural family ties. Service providers looked at the children and their families’ need for services and spoke at length about mental health concerns and the children’s need for family and peer support now and in the future. The themes that arose from the focus group discussions, interviews, and subsequent analysis are represented in Figure 3.

Figure 3

![Figure 3: Major Issues Affecting Older HIV-Infected Children](image)

The themes should not be viewed as entirely distinct from one another as many of them are cross-cutting or overlap. The issues are tentatively divided into three tiers: the top tier which is more systemic, the middle tier which is more relational or social, and the bottom tier which
is more based on the individual child’s needs. The issues at the top of the inverted pyramid represent the more cultural and structural issues that impact on the children and filter downward affecting other areas of the child’s life such as the social interactions and the factors that determine the physical health of the young person. For example, stigma in society will impact on children’s willingness to disclose their HIV status to sexual partners; acceptance by one’s peers may impact on mental health; and poverty may limit a child’s access to safe and nutritious foods. The influence is not unidirectional but may also travel from the bottom of the pyramid upwards. For example, taking medications can influence social peer interactions such as school outings. There are many ways in which all these issues may be connected to each other which will be illustrated throughout the following sections. These (4.5.1- 4.5.3) describe what’s working and what’s needed in each of the areas based on participants’ responses.

4.5.1 Sociocultural
Sociocultural issues identified by participants highlighted the need to address issues of discrimination brought about by social stigma, financial difficulties of affected families and children, nurturing children’s cultural identity, and children’s special needs and disclosure dilemmas in schools.

A. Social Stigma
Social stigma affects the HIV-positive children’s health and wellness by engendering fears about disclosing their HIV-status to people in their communities. These children live with a family secret which may have consequences for their social interactions, ability to care for themselves, and feelings of self-worth.

Social stigma was emphasized by participants as a negative and destructive influence on the wellbeing of the HIV-infected children and families. It was associated with the concepts of fear, secrecy, trust, disclosure, isolation and knowledge during the focus groups and interviews. Although there are many stigmatized conditions in society, HIV seems unique from other stigmas because it combines stereotypes associated with taboo sexual practices (e.g., homosexuality and prostitution) and illegal drug use with a fear of infectious disease and ignorance about how HIV is transmitted.

Parents illustrated the problem of social stigma with personal accounts:

- I heard “put them on an island like lepers.” Remember leprosy? They said everybody who has HIV should be put on an island somewhere. I’m sitting there listening to this thinking: there’s a few of these guys I could take out...
- A few days ago the neighbours came and they were talking about HIV... I say “maybe there will soon be a vaccine” and they say “oh, they don’t need new money for a vaccine, leave them to die, they are drunk people, they take drugs, lesbian and…” what can I say to that: “leave them to die!”?!?

Family members spoke of their fear of disclosing their status to friends and community members because of the reactions they anticipated. Children and families seem to deal with the stigma primarily by choosing not to disclose their status or their child’s status to most people in their communities. As one foster parent stated: “We have all the evidence in the
world that it is dangerous to tell. We have people blurting headlines in a place: “child in preschool has HIV”, it’s ridiculous. And it’s the craziness of some people. So you are in the closet so then there’s nobody who learns and then you have this double-edged sword of not having an opportunity to teach.” Some families are concerned that they will be ‘run out of town’ if people in the community find out that they or their child has HIV: “I mean that’s my worst nightmare that somehow, somebody is going to find out that she has HIV. Well, we’ll have to sell our house and move!” One young woman in the study explained her apprehension about telling other people: “a lot of people know who I am but I don’t really want to be like one of those people who are the centre of attention, and everybody is like, “Oh, look it! There’s the girl with HIV”’ and “I’d rather people see me as me, than people see: oh, me with HIV.” Another child participant spoke of the way her friends joke about HIV: “some of my friends or some people were like. They are drinking pop and they’re like “oh no. you might get AIDS from that…” I’m like looking at them like “oh my God, you have no idea!”” It is evident though that some of the children want to be able to tell people in their lives that they have HIV.

Stigma and knowledge seem intimately connected. Most participants expressed that there should be more education in society to help dispel the misinformation and ignorance around the issue of HIV in children. Parents and service providers spoke about how public health messages can be inappropriate for children who are already HIV-positive. These preventative public health messages may spread stigma by stimulating fear in society. Some participants stressed the need for people to have experiential knowledge of someone with the disease to promote understanding and acceptance. One young person explained: “It’s not like you have a third eye or something. I can hug you, I can kiss you; you’re not going to get it. And, people think that way. They’re just way too paranoid and way too sketchy about everything and I don’t think that people need to be more educated in the way of what AIDS and HIV is because obviously people know what it is. They need to know how people are with it...” The perceived benefit of education is increased awareness. As one child said: “they’d talk about it (HIV) more and they’d know and get used to it, kind of maybe, and then if they got used to it, I don’t know, maybe I could tell them sometime.”

Parents talked about the connection between knowledge and stigma:

- When people don’t have personal experience or knowledge of the disease, they have stigma.
- When you have a stigma about it, when you don’t know about it, you just hear the word AIDS and you just think death, you’re dying, that’s it.
- What do the public think? They think if they are shaking your hand they can get HIV...
- There’s really no advertising or information in regards to children having HIV. It’s all adults and mostly they show you... people who are on there look like drug users or gay... I think that the heterosexual community has not fully accepted the fact that they can get HIV.

Some of the strategies that have been used thus far to educate the public about this group of children include publications in “Living Positive” magazine, radio programs with the children and families, and educational sessions provided by Oak Tree Clinic and parents to
select students and professionals upon request or through conference presentations. The Oak Tree Clinic also holds educational meetings with some professionals such as MCFD social workers and school personnel when a situation (e.g., a child is threatened with expulsion) calls for remedial action.

Keeping the children’s status a secret seems to provide families with a sense of security. However, one foster parent commented on the potential negative impact of secrets: “...I think secrets mean there is something wrong and having to keep a secret means there is, well there is, the suspicion of self, that there’s something bad or different... That’s why there’s such wanting to belong and wanting to be part of us (the family). Because there is that underlying feeling of not quite good enough or “there’s something wrong with me” and I don’t want my boy to live that life.” Sometimes it is parents who want to keep the child’s HIV status a secret from others while other times it is the children themselves. Families may go to extraordinary lengths to hide the fact that a child has HIV such as taking labels off of pill bottles before throwing them in the garbage or volunteering to go on school outings so they might administer medications to their children without other people finding out. Other families have disclosed to school personnel, friends, and extended family members whom they trust to also keep the secret but, as one foster parent stated: “it’s hard to come to a place where you trust.”

Many participants discussed the problems associated with disclosing to others. During an interview, one healthcare provider stated: “I think the secret is to some extent absolutely necessary to allow them that privacy to be able to function in school and other activities.” Often, prior to disclosing to their children, caregivers will test the children on their ability to keep a secret. Some parents and providers reported that they felt isolated and that their children were isolated with the secret: “It’s good to know that there’s other people out there who are going through the same types of things that we are... you kind of feel alone, I mean my friends can’t relate...” One child participant normalized her secret and declared: “everybody has secrets.” During interviews with two older children, both said that having to keep their HIV status from their friends was a bad part of their lives.

One foster parent told a story that illustrated both the positives and negatives of disclosure:

\textit{We were blessed. When we came out for our kids we had an incident at school where it was blurted to a parent: “don’t touch that child, he’s infected.” He had a nose bleed when we were on an outing and a parent went to help. And all hell broke loose: the parent wanted him out of school. People stepped in and a group of parents in our community said: “okay, you know what, this kid deserves to be in this community, deserves to be part of it.” And we also have an extraordinary principal who said: “get into the 90s girl and start learning, get on the computer and ask your questions...” So, many of the parents know... and so they have gotten educated so the boys, when they talk to certain friends, the parents of those friends know they understand so they can support the boys if they have any questions. That’s not something that’s common. We were lucky.}

Whether or not disclosure occurs seems to depend on the context and the people involved. For example, families seemed quite comfortable with the staff at the Oak Tree Clinic and
other AIDS service organizations knowing their HIV status. Most parents seemed willing to do public presentations as long as they were located far enough away from their geographic community where no one would recognize them. Some children seemed to be more willing to disclose to other children at camp (for HIV-infected and HIV-affected children) than to their school friends, illustrated in this child’s comment: “It’s nice to go to camp because like I don’t tell any of my friends here that I have HIV. They don’t know anything of that, right. I’m just a regular kid, right… Then, when we go to camp everybody has this in common, so it’s like you can just kind of feel really relaxed and just, you know, whatever, be really, really happy, know that everything’s okay and everybody like knows and everybody’s going to support you and not sit there and feel sorry for you or change their opinion on you, kind of thing.” However, when it came to people closer to home, in their own communities and their kids’ schools, friends, and neighbours, families and children were reluctant to disclose their child’s status because they either anticipated and/or had experienced negative consequences. Interestingly a couple participants seemed to partly base their fears on the reactions that they think they themselves might have had prior to being familiar with HIV. One child said: “…if I didn’t have HIV and someone was like “I have HIV”, I might have thought like “oh, wow, like really? Stay away from that person”. Caregivers worry about their children’s wellbeing should they disclose: “we are afraid to admit it because we are afraid that she’ll be ostracized and we have an example of it that her best friend, she lost her best friend.” Conversely, some children had positive experiences when they disclosed to some friends. The size and diversity of cultural communities, such as more rural communities where everyone knows everyone else, also seemed to have an impact on families’ comfort disclosing their status. Providers reported having “incidents” over the years in communities that have required professional communication and teaching to resolve. Some children have been refused by daycares, or communities have tried to remove them from schools. However, optimistically, several participants mentioned that they thought that stigma associated with HIV has decreased over time.

B. Poverty

Poverty affects the HIV-positive children’s health and wellbeing by limiting financial independence, stability, and the ability for families to provide the healthiest options and fun activities for the children.

Financial issues were raised by many participants as a barrier to the well-being of families and their HIV-infected children. Some of the families have had financial difficulties in the past and have needed assistance with basic needs such as housing and food. Currently, the basic needs of some of the HIV-infected children are being met with the assistance of social services and programs such as those offered by Positive Women’s Network, AIDS Vancouver, and Wings Housing. However, some of the children’s families still lack financial stability and independence, as well as disposable income for recreational activities and extras like toys and vacations. And, although the HIV-infected children in foster care live in financially stable conditions, some may be affected (e.g., guilt and worry) by the financial difficulties of their birth families. Some participants highlighted that foster families have many more resources available to them as compared to familial caregivers. Familial caregivers’ income may be very limited due to factors such as poor health. The majority of families have additional expenses and/or time commitments associated with caring for their
HIV-infected child such as special schools or tutors (e.g., for learning disabilities), and costs associated with providing the quality of food and housing required to maintain their health. According to participating healthcare providers, there is no additional government funding available to families with HIV-infected children. At the present time, children must wait until they are adults to access such benefits for themselves.

C. Cultural Identity

Development of cultural identity is important to the HIV-positive children’s health and wellbeing through connecting them to their larger family and ethnic community and providing a sense of belonging. This is especially important for children in foster care and with Aboriginal ancestry.

Many participants emphasized the need to reinforce the children’s cultural and spiritual identities. Some of the HIV-positive children living with their familial caregivers are from immigrant families or are part of other minority groups. The participant discussions which emerged around this issue of cultural identity focused primarily on the needs of the Aboriginal children in foster care. About 40% of the children in this population are Aboriginal and most of these have grown up in foster care. Connection to natural and extended family was brought up as an important issue by all of the foster parents with Aboriginal children and by some of the providers as well. Challenges to the children’s developing and nurturing their cultural identities include the demanding lives of foster families, difficulties obtaining cultural information from the Ministry of Children and Family Development, the fact that many of the children’s Bands are out of province, and the need to disclose their HIV status in order for them to access certain community services.

According to some of the professional participants, part of the Ministry of Children and Family Development’s (MCFD’s) mandate is to ensure that the children in their care have opportunities to connect with their culture, natural families, and native Bands. There are cultural and spiritual events sponsored by MCFD. One foster parent spoke of the dance classes his child is enrolled in and said: “it makes her very happy — it connects her (to her culture).” Many of the foster parents travel great distances to visit their children’s relatives on holiday. As one MCFD employee explained, it is the MCFD social worker’s role to connect the children on her caseload to cultural programs and liaise foster families with children’s Bands. Therefore, a lot of work is being done by some of the families and providers in this area but it remains an important issue that needs to be addressed for many of the children in this group, especially as their identities develop further in adolescence.

D. School Issues

School can affect the HIV-positive children’s health and wellbeing by providing a place for peer interaction and a learning environment. School issues discussed centered on the issue of stigma, the educational needs of the school personnel, infection control, and school support services.

All of the children attend school. Only a few parents or children have disclosed to school personnel because of the anticipated negative reaction of the staff, the other children, and the other children’s parents. One healthcare provider commented: “Oh, they (the parents of the
Many participants in all the groups of stakeholders perceived schools as unsafe environments for disclosure. Some occasional work has been done educating school Principals and students in schools about HIV through the Oak Tree Clinic, a local school health officer, and community HIV organizations. However, this is not ongoing and is usually in response to a specific concern. Some children fear losing their friends and being ostracized by their peers. Some parents would like to be able to disclose because of safety concerns and concerns over the health of their children. As one parent stated: “I think it’s important for at least someone to know because they’re (the children) there (at school) for six hours every day and I can’t be in her class every day for six hours so someone’s got to know to look for symptoms of medication... if she hurts herself really bad, someone’s got to be very careful...” Conversely, some families have had positive experiences with their children’s schools. One healthcare provider explained her perception: “I find that the schools, provided you involve them in the planning for the kid, are almost 100% supportive and they keep their child’s HIV status confidential and they do their best to meet the child’s learning needs which may be considerable.”

School is also a place where infections can spread quickly and put the health of the children at risk – especially if no one is aware of the HIV-infected child’s compromised immune system. Many parents feel powerless in these situations because “by the time the nurse gives us the letter a week later, the outbreak has already happened.” Some children are pulled out of school by the parents whenever there are reports of infections going around in the community. Others worry that when their children miss school for medical reasons suspicions will be raised, thereby jeopardizing their secret.

Because some of the children have learning impairments and behavioural challenges, school support is important to get the children the services they need to help them learn and develop such as school aides, learning technology, etc. A few parents mentioned their child’s learning disabilities as a major challenge. Currently, some of the children have school aides to assist them but access is variable. Participants perceived that more support is needed to secure services. Schools provide children with social environments and various activities, both academic and non-academic. Some children seemed to enjoy school while others gave mixed reviews of their school experience. One child said: “I think I’d rather work than go to school. I’m not really a school person, not the greatest grades and stuff, but I like school ‘cuz, you know, I want to graduate... I like school because of friends too.”

4.5.2. Psychosocial
Psychosocial issues which emerged through the research included relationships with family and peers, the importance of recreational activities and addressing sexual health matters now and in the future.

A. Family
The children live within a family system with complex interactions. In addition to the strengths that exist, families struggle with many challenges that are stressful and can affect
the health and wellbeing of an HIV-positive child. These may include issues of disclosure inside and outside the family, resources, and health problems.

Family issues raised during the focus groups included family dynamics, family support, and education. The HIV-infected children in this group come from extremely varied family situations with some of the children living in foster care, living in double or single-parent households, or being cared for by biological grandparents or siblings. Many of the children have been orphaned from the deaths of one or both parents. It was emphasized throughout the focus groups and interviews that HIV is a disease that occurs within the system of the family and multiple generations: “it is a family infection.” The needs of children and their families are interconnected and many support each other. As one mother said: “if I’m going well, he (her son) is going well... If I am strong, he is strong.”

Many of the families have stressful lives due to illness, financial need, stigma, and caregiving responsibility. As one healthcare provider expressed: “I just feel that we need to offer more to the caregivers so that they can look after the kids and not burn out.” Some of the familial caregivers are caring for many children including non-infected siblings. They need support in areas such as resources, food, and respite. Parents also need ongoing support with disclosure and educating their children about their HIV infection. Caregivers are encouraged to begin disclosure by the time the child reaches 8 years of age but it is an ongoing process and a concern even for older children as they come to better comprehend their disease. Some participants felt that some caregivers were very protective of their children because of their disease. Some caregivers monitor their children very closely and feel like they are always nagging at their kids regarding their health: about medications, sanitation, nutrition, etc. Family conflict may arise between children and parents pertaining to health issues such as food and medications, especially as children seek more independence from their caregivers. Several participants spoke of the developmental evolution and challenges that pre-adolescence and adolescence pose, such as rebellion. One parent used the term “teenage syndrome” to distinguish between their child as a child and their child as a teenager. Since the interviews were conducted, one of the children has moved away from his family’s home and into shared housing with a friend, at only 16 years old.

Familial caregivers shared how they don’t like to talk about HIV:
• Maybe he (the child) is thinking of it inside by himself. Maybe he doesn’t want to talk to people about it... maybe one day, he will. I don’t like to talk about HIV because it makes me nervous.
• Yeah, because I don’t like to talk about it either and I don’t have HIV but because it affects me so closely.

Families seem to cope with HIV in many ways. Familial caregivers reported trying to think positively and dismiss HIV from their thoughts and they prefer not to talk about it with their children. As one parent stated: “I don’t think about it every day just when I am right now talking or going to the doctor but at home I don’t think about it.” However, they reported being reminded of the disease by medications, clinic visits, and when others talk about HIV. Some of the families are open about their HIV status within their family and family friend
networks while others are extremely secretive. Family secrecy may limit children’s options to connect with other children through social activities such as sleepovers, camp, or holidays. Disclosure of HIV status to children by parents has been a challenge for service providers and familial caregivers who may struggle with issues of guilt, their fears of exposure, and their concern for the well-being and happiness of the HIV-positive children.

B. Peer Relationships

Peer interaction and socialization are part of the HIV-positive children’s healthy development. Relationships with peers can affect them both negatively and positively. There is fear around disclosing to uninfected peers and support for socialization between infected peers.

Peers can be both a source of love and support and a source of stigma and potential rejection for these children and young people. HIV-infected children, like other children, want acceptance from their peers and this conflicts with their desire to tell their friends about their HIV-infection. Parents and service providers spoke of children’s need for peer interaction, both with children in their communities and other HIV-infected children. They recognized the need for children “to be kids” and not be burdened by adult responsibilities associated with HIV. Participants stressed that the children need friends to be healthy and happy: “they need to be with other children, they get to play, they get to do things in school that builds their self-esteem." Some of the HIV-positive children in this group have many friends and good social networks in their communities while other children are reported to be fairly isolated. Many children spoke highly of the friends that they had made at Camp Momba and one child spoke of keeping in touch with camp friends via the internet.

At the time of the study, none of the HIV-infected children had regular contact with other children whom are known HIV-infected children and many are geographically dispersed around BC. Very few children have disclosed their HIV status to any of their friends. Even at Camp Moomba, where all children are either HIV-infected or HIV-negative affected, HIV is not discussed and it is not well known who is HIV-positive among the children. Many parents and providers alike stressed the need for peer relationships to develop between the HIV-positive children and some participants mentioned that older children could act as mentors to younger children. One of the oldest children in this group stated “I’d actually like to have a friend with HIV, like, like somebody my own age or maybe like a little bit younger or a little bit older just because, then, you can relate to the same things, you’d be like: “oh yeah, I remember taking that drug and getting that.” Like you just have, like a lot, like something that’s really big in your life that’s in common with them. So yeah, I think that would be a good idea.”
Some parent and provider participants felt that peer support could help meet the needs of the children:

- Professional support is one thing and we can’t forget that one of the greatest sources of support is each other and we have to find a means to get these children together...
- I would just like to see more peer type things… I mean, she’s sick of the adults. You know, kids don’t want to deal with adults, they want to deal with kids.
- It is important to bring these kids together so they can grow as a group, as a community.
- I think there needs to be some place or there needs to be information or somehow to give them a safe place to be with people in the same boat and to be able to understand their adolescent years.
- These kids need to get together… Just so they don’t feel so isolated. So they are normalized… it’s just so important.
- If there were a bunch of kids like, she likes this group (at camp). Like, she met someone at camp, another girl around her age who also has HIV; she’s not just living in a family where somebody has it. And she would like that I think.
- I think when they’re with their peers, there’s freedom. You can just really be yourself. You don’t have to be careful.

C. Recreation

Recreation affects the HIV-positive children’s health and wellbeing by promoting peer interaction, increasing physical activity, and building self-esteem.

Some participants felt that more recreation services are needed to meet the needs of these children and contribute to their healthy development. Recreation was reported to keep the children stronger and also to help with their self-esteem by enabling them to be part of a team and to develop a skill. Currently several children take part in recreational activities, like sports and choir, both in school and out of school. Like other children they enjoy leisure activities such as skateboarding, hockey, music, and shopping. One barrier discussed by participants was the lack of financial resources to give children access to different programs such as sports teams or classes. Hummingbird Kids Society provides recreational activities to infected and affected children and their families as part of a monthly birthday party. Camp Moomba also provides yearly recreation opportunities for both HIV-affected and HIV-infected children such as kayaking. Sometimes the social stigma of HIV impedes children from participating in activities such as camp because some families, as one healthcare provider said, “just don’t want their faces shown.” However, the services also tend to focus on the younger age groups. The older children have few group activities designed to meet their needs.

D. Sexual Health

Sexual health is important to the HIV-positive children’s health and wellbeing and is becoming an increasingly important issue as they become adolescents. It challenges parents
and professionals in terms of education and support, and by raising questions about risk of transmission, responsibility, intimate relationships, and family planning.

Currently, the children are receiving HIV-related sexual health information from the healthcare providers at the Oak Tree Clinic and within their families. As one healthcare provider explained: “they know that if they decide they’re going to have sex, they need to talk about it with their partner and use a condom and they know all that stuff, because we probably talk about it and talk about it until we’re getting on their nerves.” They also receive information about sex and HIV from their peers, at school, and in the media, much of which is negative or stigmatizing. One healthcare provider emphasized the need for kids to have positive sexuality: “I think give them a positive approach to their sexuality... It can get tainted so easily because these kids are so in touch with community resources... and a lot of them know about HIV... seeing posters saying HIV, safe sex, all that stigma, all that anti-sexuality... (they) need to feel positive about their bodies and sex.”

The focus group and interview discussions about sexual health tended to centre around concerns about providing sexual education, sources of sexual education, concerns about sustaining romantic relationships and partner disclosure. Parents vary in their willingness to discuss these issues with their children and the children vary in their readiness to receive the teaching on these topics from parents. During the discussions with participants, some caregivers expressed a need for education and support in order to provide guidance to their children about sexual health. Sexual health raised many questions for some caregivers such as those of one parent: ”like what do you say to them? I mean are you (the child) allowed to go on a date? Are you allowed to make out with somebody? What do you do? Do you reveal your whole medical issue to the person?” Some of them also expressed their apprehension with dealing with the issue of sexuality with their children as demonstrated by this comment: “I think it’s tough enough to deal with the sex thing as it is or the puberty thing as it is, let alone to have to deal with the HIV and the puberty.” Some parents still regard their children as too young for the information, even as young teenagers. Conversely, one service provider stated: “By 11, they are teenagers. So we need to look at that demographic and consider that these kids could be having sex.” Service providers spoke of the need for tools to deal with the children’s sexual development in the future.

Many of these children are starting to be curious about developing romantic relationships and about sexual activities. Unlike other children, their sexual health is complicated by their HIV from the very beginning of their sexual development. Some of the older children have already had sexual experiences and/or have romantic relationships. Although they are educated by healthcare providers and parents to disclose their status to their sexual partners, some express concern about maintaining a relationship when they disclose to their boyfriends or girlfriends. One young participant explained his approach to relationships: “...in the future, if I’m still going out with this person and we eventually want to have sex, I’m going to have to tell her this (his HIV status), ’cause you know, I just think that she should know before having sex with me. It’s just like that. Like having kids, you know? I really want to have kids and that’s going to be; I guess it could be an issue. I guess maybe it couldn’t. I don’t know though.” These issues of sexuality, partner disclosure, and family planning are
going to be an increasing concern as more of the children enter adolescence and approach adulthood.

4.5.3. Psychomedical

Current and future psychomedical issues identified by participants included concerns about mental health, the importance of good and accessible nutrition, children taking their medications, challenges with multiple diagnoses, and concerns about physical health.

A. Mental Health

*Mental health affects the HIV-positive children’s health and wellbeing by impacting on their feelings and their sense of self. These children face exceptional challenges including grief, secrecy, and acceptance from others and within themselves.*

Many participants raised mental health needs and concerns around children’s emotions, bereavement, feeling “normal”, permanency, security, stability, self-esteem and having a positive attitude. Some of these children access counselors in communities and/or are assessed by a psychiatrist at the Oak Tree Clinic. Others receive support from friends, family, healthcare providers, or religion. As one healthcare provider explained: “Well, they’re (the children) not talking to very many people about it. They’re talking to their parents who give them tons of support around it, really lots of support and good vibes and good feelings and reassurances and things. They talk to us...” Many participants felt, however, that more ongoing support is needed. Participants spoke of how the children have worries and anxieties that most other children their age do not have to deal with such as having their parents die before they can adequately take care of themselves, and being rejected by a girlfriend or boyfriend when they disclose their status. Mental health can also be influenced by a number of HIV-related and HIV-unrelated issues such as opportunistic infections, fetal alcohol syndrome (FAS), neonatal abstinence syndrome (NAS), learning disabilities, and financial hardship.

Participants expressed mental health needs that arise with these children:

- *Kids need therapy whether it is around their issues about grief and loss, their anger or whatever it is that’s going on – they need some kind of support throughout the year.*
- *One of my biggest concerns about being a teenager, whether you’re positive or not, is that kids become suicidal and the kids that we work with – we’re dealing with kids who are positive and affected and suicide is a big issue...*
- *Many of these children have already undergone losses of a parent or in some cases a sibling, especially around HIV... they need bereavement help*
- *(My son) goes blank, he smiles, his eyes get glazed over and he just... you can tell he’s left... He’s not hearing a word you’re saying as soon as you start talking about his mom or HIV or anything like that...*

Parents and providers stressed the need for the children to feel “normal”. Most participants stated that these children need to feel accepted and feel that they belong in their communities and families. As one participant put it: “*they (the children) need a sense of belonging, that*
they are part of something.” At the same time, it was acknowledged by many participants that these children are different from their peers because they are on medications, because they need to go to the clinic and have medical procedures, because they have lost a parent, because some of them cannot enjoy activities such as sleepovers and because they have to live their life with a secret. It was not clear from this study what impact the secrecy has on the children’s mental health; however, one child expressed her frustration with the stigma of HIV and proceeded to say: “I just want to feel comfortable with people if I am telling them, you know, like I don’t feel comfortable with anyone.” Children who are in good physical health and without disabilities seem to be better able to keep their HIV status a secret. Because they do not require any special care in the school system and/or have no visible differences from uninfected children, they may be better able to fit in with their peers. One of these children stated during her interview: “I’m just a regular kid, right. Well, I am a regular kid but, I mean, I do have a disease.”

One healthcare provider commented on the children’s home environment as another facilitating factor: “their emotional reactions vary but ones who are in really supportive living situations seem to be able to accept the HIV as just something that they’re dealing with and they kind of get on with their life, and have fun, and have friends, and act like a normal kid; play hockey, do whatever.” The concept of “burden” also arose frequently during the focus group and interview discussions. Caregivers and providers were concerned about the psychological burden that may result from the children being aware of their HIV diagnosis. This concern is reflected in caregivers’ comments such as: “That’s a weight that I have to carry because I’m an adult. So for kids, they should not have this weight on their shoulder. They should be allowed to be free and be kids, be normal” and “I don’t think that the child should be burdened with it. It’s a burden to the child. It’s too hard on the child. It should be uninhibited and happy... She shouldn’t think about it.” These concerns may serve to reinforce the secrecy surrounding their disease.

Maintaining a positive attitude seems to play a role in the ability of families and children to live a “normal” life. As one healthcare provider commented: “To have hope and not dwell on your illness is healthy.” This creates an interesting and critical challenge for service provision. For example, despite the perceived need for mental health services, some of the children and caregivers were very clear that they would not like to participate in support groups that involved talking about their disease and problems. Two of the children shared their thoughts about this: “because if you think about it a lot then you’re always going to be like down and stuff like that; always looking for some comfort and stuff and I don’t want to do that” and “If you are positive, you’re probably a little more healthier than being: “oh, I’m going to get sick and this is never going to go away or anything.”” However, there are many factors in these children’s lives that put their mental health at risk and these need ongoing attention to promote the children’s wellbeing. For example, children in this age group often present challenges to caregivers and providers when it comes to taking medication consistently, sometimes leading to psychiatric referrals. Attitudes and emotions may vary depending on the children’s adjustment to their disease and life and on what services are made available and accessible to them.
B. Nutrition

*Nutrition influences the health and wellbeing of the HIV-positive children through physical processes of nourishing the body, medication side-effects, family dynamics, body image, and accessing safe and nutritious foods.*

The concerns about nutrition that arose during the study included the issue of accessing safe and nutritious foods and the specialized clinical nutrition therapy for their HIV and related problems. Nutritional concerns have changed over time and as the children age into adolescence with fewer concerns about failure to thrive and more common teenage issues such as their lifestyle and food choices (e.g., low activity levels and high fat foods). Some children and parents have experienced challenges with nutritional side-effects of antiretroviral medications such as loss of taste, appetite changes, constipation and high cholesterol. One healthcare provider noted the extreme differences in appetite of children when they are on and off medications: “as soon as they have a break in those medications, they start eating like a horse. Their appetites really improve. They all of a sudden gain a whole bunch of weight... then they’ll have to go back on the medications eventually and then you see a sort of shutdown...”

Children with HIV may eat very slowly which can make it difficult for the children to meet their nutritional requirements — especially when they have limited time in settings such as school. Some children have food supplements before or after school to provide additional nutrients that they miss during the school day. There are a few children who have needed to have feeding tubes as a supplemental feeding strategy to treat nutritional deficiencies and failure to thrive. Body image problems were also mentioned by participants as a concern — especially as the children get older and/or develop abnormal fat distribution associated with antiretroviral therapy. Other future concerns regarding nutrition voiced by participating healthcare professionals include cardiovascular disease, diabetes, and osteoporosis.

Parents and providers work together to meet the nutritional needs of these children. One healthcare professional who participated in the study had this to say about children’s nutritional needs: “they just need to have a good nutritious diet and get lots of nutrients like every kid but the consequences of not doing that are more severe in this population than in a healthy child.” Currently the Oak Tree Clinic has a full-time dietitian who provides families and children with individualized nutritional counseling on a one-to-one basis during their medical appointments (approximately every three months). Children begin to see the clinic.

Participants in all the focus groups emphasized the importance of food:

- They need a good source of food, healthy food, delivery, those things... there are some very specific issues about the infected children around food... they all have food issues...”
- Eating is the most important thing
- I’m just on to meds and eating properly
- I’m thinking you know that perhaps because we don’t know the long-term effect of the virus or the drugs for that matter, I think there should be a little more emphasis on watching effects of the children’s diet...

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31 People with HIV may experience subcutaneous fat loss (lipodystrophy) and inappropriate visceral fat accumulation belly, dorsocervical, and breast areas (Dietitians of Canada and the American Dietetic Association).
dietitian by themselves at about age 11 and they learn about foods with food models and are encouraged to make their own lunches or start choosing foods. All of the children in this group were reported by their participating healthcare professionals to have current access to safe and nutritious foods at home; however, food security is an ongoing concern for familial caregivers with low incomes. Families can access the food banks and other services at AIDS Vancouver, PWN, and Loving Spoonful, and some children participate in a school meal program. Children take vitamins and other supplements recommended by a dietitian and many enjoy an active lifestyle. At home, parents use different strategies to provide children with healthy foods including juicing, blender drinks, catering to children’s likes and dislikes, and providing a variety of foods and a balanced diet. A few parents mentioned using complementary therapies including nutrition supplements such as herbs, amino acids, and silicates. Those who chose to explore these options expressed that they felt “alone”, wanting more support from professionals in strategizing holistic treatments.

The family dynamics around food are complicated by the child’s HIV status. Families may see food as a means of nurturing and conveying love for their children, as a means of fighting disease and maintaining health, or as a subject of conflict between children and caregivers. Some families may find it hard to empower their children to take care of their own nutrition because, as one provider said, “it is much easier to just do it themselves” and the various meanings given to food may make it difficult to support the child’s self-sufficiency in food selection and preparation.

C. Medications

*HIV medications are credited with keeping the HIV-positive children alive and as healthy as they are today. Although many improvements have been made, concerns around adherence and social challenges still exist when it comes to antiretroviral therapy.*

Most of the children are on triple combination antiretroviral therapy to improve and/or maintain immune function. In some cases, children may need other medications to control HIV symptoms or side effects related to the HIV therapy. Others may need medications for medical conditions unrelated to HIV. A couple of the children in this group are on “drug holidays” (treatment interruptions) because of their good health status. Currently all the children have access to antiretrovirals through the Oak Tree Clinic. These medications are 100% covered by the Provincial drug treatment program for all BC residents. Although most children still hate taking their medications, HIV medications were reported by many participants to have improved significantly over the past ten years. In recent years, more simplified regimens have decreased the number of pills and frequency required for medication administration. One parent gave this example: “And they don’t all have to be kept in the fridge so you can go away on holiday or you can go away for the whole day without worrying about a fridge or a freezer pack or something.”

During the focus groups, concerns around medications were raised by many participants because of the challenges of their long-term medication regimes and how they can impact on the children’s social lives and serve as a reminder that they are different from other kids. A service provider explained: “they would love not to have to take their meds... especially in situations like sleepovers, camp...” One parent explained his struggles with getting his child
to take the medications: “she hates them right, I mean who wouldn’t, she’s taking all these drugs all day long but she’s trying to find ways out of it... (she says:) “I feel fine, why do I have to take them?” Another caregiver spoke of his concern regarding resistance to medications and the limited number of options left for his child since she has developed a resistance to many of the medications on the market over her lifetime.

Parents had different strategies for ensuring that their children took their pills including observation, alarms, and pill cases. Some have given their children the responsibility over their own medications while others continue to give reminders and help administer the medications. Medications are a big responsibility for both parents and children. As one of the parents remarked during an interview: “she’s got to think about medicine all the time, so, most kids got to think about brushing their teeth.” Conflicts arise around medications in families: “like everything it starts when they’re teenagers cuz they want to be kind of defiant and they’re sick of it... it’s impossible to monitor every single time.”

There are some concerns that children will become less adherent to medications once they approach and reach adolescence. As one healthcare provider explained, developmentally, pre-adolescence and adolescence are stages when there is a tremendous need to conform with peers, feelings of invulnerability and immortality, and a process of separating from parents and establishing one’s own values and identity, which could potentially contribute to these young people not taking their medications as prescribed. This can be particularly true when children are feeling well and it may be difficult for them to understand the direct benefits of medications. Side-effects and having to take medications regularly and over the long-term can also create challenges in terms of young people’s adherence. However, the adolescents who participated in this study seemed to have a good understanding of the importance of taking medications illustrated by one young person’s comments: “I’d hide them like in my socks or I’d hide them in my pockets or I wouldn’t take them because I, you know, I was a lot younger. I didn’t realize how much they do help me and how much they’re probably going to help me in the future...”

The act of taking medications seems to function as a conscious daily reminder to the children that they are HIV-infected. Adherence may be influenced by the fact that most parents and families prefer not to think about their HIV. Administering medications to children may pose a special challenge to parents who are themselves unwell. Sometimes parents are not taking their own medications. Also, adherence seems to be affected by the stigma of infection as children generally must take their medications in private if they want to keep their secret and prevent others from asking questions.

D. Multiple Diagnoses

Some of the HIV-positive children face additional health issues such as FAS, NAS and learning or behavioural problems.

Unlike many of their HIV-positive counterparts in other parts of the country, many of the children in the BC group were exposed as fetuses to illegal drugs and alcohol. As a result, many of the children in the group have disabilities and behavioural issues associated with Fetal Alcohol Syndrome (FAS) and/or Neonatal Abstinence Syndrome (NAS) and may be
developmentally delayed. These issues are seen by some parents and providers as more problematic than the HIV itself. As one parent said: "I think her FAS is more a concern than the HIV". At least one foster parent attends a regular parents’ FAS group meeting. Also, some children in this group who were not exposed to drugs also have difficulties such as learning disabilities and Attention Deficit Hyperactivity Disorder (ADHD). This multitude of special needs poses ongoing service and family challenges as the children mature.

E. Physical Health

Health status is variable amongst the HIV-positive children and, although quality medical treatment is provided to them, concerns exists around keeping children physically healthy over the long term.

Although participants agreed that the children are living healthier lives in recent years, the health status of the older HIV-infected children in BC is extremely variable. Some of the children have had no symptoms their entire lives, whereas others have struggled with severe illness and compromise of their immune system, sometimes requiring hospitalization. Some of the children appear completely healthy while others have external signs of illness such as feeding tubes or disability. Children with poor health or intermittent health problems may experience more challenges such as missing school and may require more time-intensive medical attention than other children. The children’s physical health may be influenced to different degrees by all of the environmental, psychosocial, and medical factors discussed above. As well as accessing the services available at the Oak Tree Clinic, the families and children visit their family physicians and some seek out alternative therapies such as naturopaths and herbal medicines. Concerns regarding future physical health of some of the children remained an important issue for many participants in the study.

4.6 What Can be Done?

The HIV-infected children’s needs are many, varied, individual and shared. There is not one single problem or one single solution. The range of challenges that they may be facing or may soon face can be approached from many directions. Some of the issues are being addressed in a comprehensive manner such as clinical care needs while others demand a strengthened response such as the children’s educational and support needs around issues of sexual health, mental health, and social stigma.

4.6.1. Future Planning

This population of children is quickly approaching adolescence and adulthood and becoming more independent. They face unique challenges regarding self-care, life skills, and health in areas such as nutrition, housing, and medications. They need long-term education strategies as they reach adulthood and issues arise such as having their own families and/or launching their careers. As one provider asked: “What programs can be provided to these kids to give them strength and purpose as young adults and not become a product?...” Parents have a role as well. For example, like other parents, they can make their children’s futures more secure in the event something should happen to them. As one provider suggested, parents
need to “do a will and make arrangements – they (the children) need more of a security of a future so they are not at risk for being passed around.” Family members and children need resources and support to deal with the uncertainty in their lives and plan for the future.

These children’s needs are highly variable depending on the individual child. Some of the older children already have started working part-time while they are in school and one was reported to be saving up money for his education at 13 years old. However, many of them have challenges when it comes to vocational planning and life skills because they have such specialized needs and because of their multiple diagnoses. These children have higher and more complex needs than many of their peers and they will require knowledge and support to care for themselves. For example, infected teenagers and young adults cannot afford to eat poorly or reside in unsanitary conditions as many of their counterparts would normally be doing at that stage in their lives. Some participants stressed that children need guidance on topics such as managing their own diets and medications as they get older. Fortunately, unlike many other groups of young people with HIV, these children are able to continue receiving specialized medical care from the Oak Tree Clinic throughout their adolescent years and into adulthood. However, social and community services currently do not offer a comprehensive continuum of care to HIV-infected children.

The children in this group represent a range of ages and an even greater range of developmental stages. Children may feel uncertain about their futures and that they do not have a lot of control. As one child commented: “I still think I’m just one of those people, the future comes and whatever it throws at you, it will throw at you. Who knows? You just gotta like base things day from day because you have no idea what is going to be in the future. You can’t be like, “Oh, yeah. I’m going to go to college and become a veterinarian and live in a big house and live in a mansion and have five kids and a dog and a cat.” It’s obviously not going to work like that at all, at all. But obviously I worry about things like that, you know. I kind of think about things like that but I don’t really, I don’t try to let them bother me right now because I don’t see why I should, because I’ll have time to worry about it later.”

4.6.2. Action Strategies
To address the needs identified throughout the various focus groups and interviews, participants were asked to come up with strategies for action. They focused on those that they thought were most important and realistic, reflecting on services currently available in the community and challenges such as transportation, and the geographic isolation of some families. Whether or not the actions should be achieved within individual families, on a case-by-case basis, or through broader community programming for groups was also discussed. These action strategies are divided into five broad categories based on the primary researcher’s analysis:

- Peer-based programs for kids
- Professional services
- Support programs for families
- Educational programs for communities
- Research
Strategies are illustrated in the following pages (Figure 4) accompanied by some of the descriptive details outlined by participants during the focus groups and interviews. This included suggested individuals and/or organizations that could take responsibility for them.

The strategies focused on education and support. Many groups need education and support around the issues of HIV: the children themselves, their families, professionals, communities, and society at large. Education needs for the HIV-infected children include sexual health and having HIV. Many older children have started asking more questions and showing an interest in these issues. Many of the participants thought that education should come from a variety of sources: other HIV-positive and non HIV-positive children, parents, and healthcare providers at Oak Tree Clinic. Some parents expressed how they wanted their children to be able to get information on their “own terms” and to form their own opinions on the issues. Parents, for themselves, wanted continued support and guidance from the Oak Tree Clinic and other sources on how to approach difficult topics with their children.

Participants suggested that GPs, financial workers, social workers, parents and school personnel should be especially targeted for education about pediatric HIV. As one social worker in the group expressed: “I just find for me, as a social worker, the type of education that we are talking about (sex, HIV); I have at times felt overwhelmed with the nature of that.” Currently, the Oak Tree Clinic is educating key people in communities (e.g., a counselor) to work with these families as the need arises. Train-the-trainer initiatives were suggested by one provider to help build the professional knowledge in other communities outside of Vancouver. Educational needs of communities focused on counteracting negative public perceptions based on media images that tend to focus on adults and present stigmatizing information. Some family members and children expressed interest in providing education to others regarding HIV; however, they were also hesitant to participate in activities because of the potential risk of exposing themselves and/or their children to stigma.
### Figure 4: Matrix of Action Strategies

<table>
<thead>
<tr>
<th>Theme</th>
<th>Action</th>
<th>Description</th>
<th>Responsible</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Peer-based Programs for Kids</strong></td>
<td><strong>Facilitated youth group for infected children</strong></td>
<td>The children/youth could get together for recreational activities on a weekly or monthly basis. They could have information sessions that could include expression through art, music, etc. Perhaps a youth worker could plan events and/or visit children individually. However, it is difficult to bring the kids together because they are geographically dispersed.</td>
<td>AIDS Vancouver, YouthCo, or another community agency</td>
</tr>
<tr>
<td>****Virtual camp or e-group for infected and affected children</td>
<td>The children/youth could access the internet from wherever they live in the province. There was a suggestion made that there be a chat-room or separate e-group for HIV-infected kids. Variables to consider include that some children may have difficulty communicating through the written word and that the e-group would require monitoring by an agency.</td>
<td>Camp Moomba</td>
<td></td>
</tr>
<tr>
<td><strong>Buddy system or mentorship program for infected kids</strong></td>
<td>Kids would be connected one-on-one with other kids so that they can communicate via phone, email, writing, etc. Also, older kids could be paired with younger kids so they have positive HIV-positive role models.</td>
<td>Oak Tree Clinic (OTC) could facilitate</td>
<td></td>
</tr>
<tr>
<td><strong>Drop-in centre for infected and affected kids</strong></td>
<td>Infected and affected children could congregate and receive support at a specific location in the Lower Mainland.</td>
<td>Camp Moomba and parents</td>
<td></td>
</tr>
<tr>
<td><strong>YouthCo presentations</strong></td>
<td>To meet their educational needs about sexual health and HIV, children and youth could be brought together for an educational presentation by youth educators such as those at YouthCo AIDS Society.</td>
<td>YouthCo with OTC facilitation</td>
<td></td>
</tr>
<tr>
<td><strong>Professional Services</strong></td>
<td>Outreach mental health worker for infected children</td>
<td>An organization could apply for funds to hire an extra staff member in order to have someone who could liaise with schools, assist with sexual education and developmental, psychosocial issues, as well as coordinate with other community organizations to provide services.</td>
<td>OTC and/or community agencies</td>
</tr>
<tr>
<td><strong>Educational resources for children</strong></td>
<td>Providers could adapt adult educational materials to a youth-friendly format. For example, some materials are currently being translated for use with English-speaking children to teach about HIV and self-assessment and management skills.</td>
<td>OTC, YouthCo, etc.</td>
<td></td>
</tr>
<tr>
<td><strong>Booking appointments together for older kids at clinic</strong></td>
<td>The children come in for appointments about every 3 months. Booking appointments together would give the children an opportunity to connect initially and then they could request to be booked together. This could also involve hosting activities for the children.</td>
<td>OTC</td>
<td></td>
</tr>
<tr>
<td><strong>Wellness program</strong></td>
<td>A 6–8 week program with a skilled trainer (e.g., similar to those for abused children) could be developed to assist children/youth with a number of psychosocial issues.</td>
<td>Unknown</td>
<td></td>
</tr>
<tr>
<td><strong>Alternative therapy</strong></td>
<td>A community-based or hospital-based organization could offer alternative therapy services (e.g., play, art, and music therapy) to support kids in an ongoing way. Due to geographic dispersion, this might be achieved through individual referrals to community services (e.g., hospice services).</td>
<td>OTC, Camp Moomba, MCFD, etc.</td>
<td></td>
</tr>
<tr>
<td><strong>Cultural activities for children</strong></td>
<td>Children need to be connected with cultural activities in their communities.</td>
<td>Parents with support from MCFD, OTC</td>
<td></td>
</tr>
<tr>
<td>**<strong>Education for parents</strong></td>
<td>Some parents feel that they would like to be more informed about HIV. This would simultaneously allow families to exchange information with each other and with professionals. For example, some parents express a desire for more creative nutrition strategies such as blender recipes and monitoring diet so they could share notes. Another strategy may be to develop educational material to help families deal with issues such as disclosure to children.</td>
<td>OTC</td>
<td></td>
</tr>
<tr>
<td>Support Program for Families</td>
<td>School notification regarding infection</td>
<td>Parents who have chosen to disclose to school personnel may request a phone call when there is an infectious outbreak.</td>
<td>Parents and schools</td>
</tr>
<tr>
<td>-------------------------------</td>
<td>----------------------------------------</td>
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<td>------------------</td>
</tr>
<tr>
<td><strong>Buddy program for families</strong></td>
<td><strong>Recreational activities</strong></td>
<td>Families caring for HIV-infected children could be put in touch with other families caring for HIV-infected children for friendships, support, information, respite, and mentorship. Another option is families from the community could volunteer for a year to support affected-families.</td>
<td>Unknown</td>
</tr>
<tr>
<td><strong>Group for families of HIV-infected kids</strong></td>
<td><strong>One-to-one parent support</strong></td>
<td>Parents could connect to other parents through an e-group to share information regarding care of children, support, etc.</td>
<td>Unknown</td>
</tr>
<tr>
<td><strong>Financial assistance</strong></td>
<td><strong>OTC could facilitate, Camp Moomba</strong></td>
<td>Parents need to educate their children around issues like sex but would like support as they go along.</td>
<td>OTC</td>
</tr>
<tr>
<td><strong>OTC</strong></td>
<td><strong>Assisting families with medications</strong></td>
<td><strong>OTC, Health Authority</strong></td>
<td>Government</td>
</tr>
<tr>
<td><strong>OTC can support parents and kids through case management and finding appropriate strategies for children’s needs; perhaps an outreach nurse to assist with medication administration.</strong></td>
<td><strong>OTC</strong></td>
<td>Government</td>
<td></td>
</tr>
<tr>
<td><strong>Educational Programs for Communities</strong></td>
<td><strong>Train-the-trainer</strong></td>
<td>Professionals could train other professionals in communities around the province about HIV-infected children and families in order to de-centralize the knowledge.</td>
<td>OTC</td>
</tr>
<tr>
<td><strong>Education sessions for professionals and parents</strong></td>
<td><strong>Education in schools</strong></td>
<td>In order to curb the stigma around HIV, educational messages and resources should be targeted at MCFD social workers, financial workers, school personnel; GPs, people responsible for social programs, and other professionals; other kids’ parents through PAC; school boards at the level of policy and curriculum planning.</td>
<td>Family members, professionals (OTC, AIDS Vancouver, etc.)</td>
</tr>
<tr>
<td><strong>Education for foster parents</strong></td>
<td><strong>Education for foster parents</strong></td>
<td>HIV education targeted at children in schools would inform other children of the experience of children living with HIV in addition to delivering prevention messages. This could involve a trained educator visiting various schools to provide education.</td>
<td>Professionals, parents, HIV-infected youth</td>
</tr>
<tr>
<td><strong>Media campaign</strong></td>
<td><strong>Media campaign</strong></td>
<td>Many foster parents are unwilling to take HIV-positive children because of their ignorance about HIV. This HIV education could take place during foster parent orientation sessions.</td>
<td>Parents and professionals</td>
</tr>
<tr>
<td><strong>Nutrition</strong></td>
<td><strong>Nutrition</strong></td>
<td>Advertisements that realistically represent families and HIV-infected kids may help to counteract negative stereotypes presented in the media such as illegal drug use, etc. This might include placing advertisements directed at kids in school, writing letters or articles for the paper, or contacting the television media to show informative news clips.</td>
<td>Parents and media</td>
</tr>
<tr>
<td><strong>HIV-affected children</strong></td>
<td><strong>HIV-affected children</strong></td>
<td>Research is needed to examine not only infected children’s needs but also the needs of affected children who are not infected but live with infected parents or siblings.</td>
<td>Academics</td>
</tr>
</tbody>
</table>

** Indicates action strategies suggested during more than one focus group
4.6.3. Additional Suggestions for Action
Considering the discussions which emerged during the course of the study and through connecting with various agencies in the community, the author of this report (primary researcher) suggests these additional actions:

- Creating resource lists for teens to address educational needs such as HIV, medications, and sexual health. These may include websites (e.g., www.livepositive.ca, the Canadian AIDS Treatment Information Exchange, YouthCo, and CiberIsle), books, movies, and other material accessible through various agencies.
- Developing a network and directory of Canadian service providers to create a forum for the easy exchange of information and problem-solving about issues such as emerging research, clinical practices, and workplace stress.
- Developing or adapting written materials to assist children and youth with disclosure to sexual partners and friends.
- Establishing referral or in-house counseling services for adolescents to address issues such as HIV disclosure to sexual partners, grief, and stigma.
- Delivering pediatric HIV educational sessions at provincial universities for students training in the fields of education and the various health professions.
- Developing a newsletter for older children and/or families with HIV.
- Developing an education kit to facilitate interactions with schools. This may include existing resources (e.g., children’s storybooks) which address HIV in childhood.
- Forming links between clinical services such as Oak Tree Clinic and youth programs such as the youth program at Children’s and Women’s Health Centre of BC or the adolescent health program at GF Strong to provide youth with resources and share ideas around programming for youth.
- Integrating teen-friendly education about sexual health and HIV into recreational activities for older children (e.g., camp).
- Linking children to materials and activities offered through other organizations such as the National HIV Network for Children, Youth, and Families (Canadian AIDS Society).

4.6.4. Recommendations for Future Interventions
The needs and strategies outlined in this report have several implications for future research, practice, and policy around service provision for older children with perinatally-acquired HIV in BC. Recognizing that constraints exist which include limited time of children/youth, caregivers, and service providers; limited funds available for programs; geographic dispersion of HIV-infected children and adolescents around BC; and the need for confidentiality due to the social stigma which exists in the broader society, recommendations for future interventions include:

- Interventions should use a population health approach, recognizing that needs of older children, adolescents, and young adults are multifaceted and influenced by biological, developmental, social, and environmental factors.
- Interventions should include intersectoral collaboration including healthcare, education, and social services.
- Decision-makers should involve families and young people in the design, implementation, and evaluation of programs meant to meet the needs of the children.
- More research is needed to identify service models that are effective in meeting the various needs of young people with pediatric HIV.
• Young people and families should be empowered and enabled through education and support to seek ways of meeting their own needs and making choices about their health and healthcare.
• Interventions should seek to build the capacity of children and adolescents in areas such as life skills, leadership, and communication.
• Interventions should respect the diversity that exists in this population and include flexible, culturally-sensitive and culturally-nurturing activities.
• Interventions must recognize the extremely sensitive nature of HIV in children and clearly communicate provisions surrounding confidentiality and informed consent.
• Interventions should seek to build community and increase communication between the various stakeholders involved in the care of older children and adolescents with HIV.
• Policies regarding financial and social support of HIV-affected families should be examined to ensure equitable allocation of resources.
• Interventions should seek to help families and young people adjust through the various stages of child and adolescent development.
• Interventions should include not only a family-centered but also a youth-centered approach, recognizing young people’s growing independence.
• Partnerships between the various service agencies, professionals, and researchers should be strengthened to ensure evidence-based quality programs, mutual support, and limited duplication of efforts.
• Knowledge and wisdom gained from the experiences of service providers, caregivers, children and young people should be translated and shared with various stakeholders, agencies, and audiences through open communication.

Conclusions
In summary, HIV-infected children in BC are getting older. The needs that currently exist and that will evolve as the children and adolescents mature are complex and variable and may require coordinated efforts and both individualized and social programming. Shared needs of the children include those related to issues of sexual health, mental health, and stigma. There are many positive influences in the lives of older children living with HIV in British Columbia. Among them are the strengths of the families and children themselves and the supportive network of clinical and community service providers. As a result, many of the needs of the children are currently being addressed in many ways. However, as the years pass, age-appropriate programs are needed to nurture children through the various stages of development into adulthood, including social programs that continue to educate and support them during times of great transition and self-discovery.
Works Cited


Diagram of Older HIV-Infected Children’s Needs

- Education & Support
  - Able to provide stable, secure, stable, supportive home environment
  - Open, honest, and attentive
  - Able to attend to needs of children and themselves
  - Able to provide cultural and spiritual support
  - Able to provide opportunities for education and recreation
  - Networked to other HIV-affected families

- Community
  - Confidence and self-esteem
  - Sense of belonging to family, peer group, community and culture
  - Future opportunities
  - Spending money
  - Support and education from peers, family, professionals, and community
  - Love and hope
  - Recreation and travel
  - Positive role models
  - HIV-positive peers and role models
  - Medication and clinical services
  - Healthy foods and stable housing

- Professional
  - Non-stigmatizing and informed
  - Include supportive friends, schools, neighbours, and community services
  - Able to provide environmental stability

- Family
  - Able to provide informed services including medical, psychosocial, and cultural
  - Are part of a supportive professional network
  - Able to provide advocacy for families
  - Able to provide services to meet medical and psychosocial needs of families
  - Able to provide high quality of care and are knowledgeable about HIV
  - Able to provide consistency of care with low staff turnover in organizations that provide services
  - Friendly and supportive of children and families
  - Able to provide a continuum of care for children into adulthood
  - Able to provide holistic care

- Child Development
  - Friendly and supportive of children and families
  - Able to provide holistic care

- Child
  - Networked to other HIV-affected families
  - Able to provide informed services including medical, psychosocial, and cultural
  - Are part of a supportive professional network
  - Able to provide advocacy for families
  - Able to provide services to meet medical and psychosocial needs of families
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  - Able to provide holistic care

- Non-stigmatizing and informed
  - Include supportive friends, schools, neighbours, and community services
  - Able to provide environmental stability

- Education & Support
  - Able to provide stable, secure, stable, supportive home environment
  - Open, honest, and attentive
  - Able to attend to needs of children and themselves
  - Able to provide cultural and spiritual support
  - Able to provide opportunities for education and recreation
  - Networked to other HIV-affected families

- Community
  - Confidence and self-esteem
  - Sense of belonging to family, peer group, community and culture
  - Future opportunities
  - Spending money
  - Support and education from peers, family, professionals, and community
  - Love and hope
  - Recreation and travel
  - Positive role models
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  - Friendly and supportive of children and families
  - Able to provide a continuum of care for children into adulthood
  - Able to provide holistic care
Appendix C: Needs Assessment Community Report (Child)
Research Summary for B.C. children and youth born with HIV/AIDS

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Research Summary

What can be done to help older HIV-infected kids live positively?

“When I hear the word living positive… it’s PMA to me, positive mental attitude. It’s about living your life and taking the best you can from whatever you can.”

• Background:
A lot of children born with HIV in the province of British Columbia are becoming teenagers and young adults. This study was trying to get at what HIV-positive kids and teens need to be healthy and happy and what else needs to be done to make sure that happens. To find this out, group interviews and one-on-one interviews were done with different groups of people involved in your lives. To get a big picture of what’s going on with all the kids born with HIV in British Columbia, we asked kids, family members, and professionals’ questions about the good and bad things in your lives and what can be done to make things better. From the interviews, everyone’s ideas were grouped together under headings to get at the main points that came up with each of the questions that were asked.

• Who was part of the study?
There were 3 groups of people who participated: 10 kids over 8 years old, 11 family members, and 11 professionals and people from social programs (like Hummingbird Kids Society and Camp Moomba). The kids ranged from 9 to 16 years old and came from a lot of different ethnic backgrounds.

• What are the good things for HIV-positive kids in BC?
Adults said that the support of family and friends, better medications, and having access to a lot of different professionals (like nurses, doctors, social workers, etc) were positive things in your lives. You also talked about the fun activities that you do like family holidays, skateboarding, and camp. The picture on the next page shows all the different services that kids with HIV in B.C. can use.
What do HIV-positive kids in BC need?
Different HIV-positive kids need different things. The things that the adults and kids brought up in study were things like good nutrition, medications, good physical health and healthcare services, good friends, help for families, recreation, good schools, cultural activities, and having enough money. One major thing that came up was that kids born with HIV need help dealing with hard stuff like the death of a loved one or telling other people that you have HIV. Also, some of you have questions about boyfriends and girlfriends and having a family of your own one day. It also came up that it is hard to talk about HIV because it can be scary and you can’t tell what people will say and do when they find out. But a lot of you would like for it to be easier to talk about being HIV-positive.
I’d actually like to have a friend with HIV, like, like somebody my own age or maybe like a little bit younger or a little bit older just because, then, you can relate to the same things, you’d be like: “oh yeah, I remember taking that drug and getting that.” Like you just have, like a lot, like something that’s really big in your life that’s in common with them. So yeah, I think that would be a good idea.

In the future, if I’m still going out with this person and we eventually want to have sex, I’m going to have to tell her this (his HIV status), ‘cause you know, I just think that she should know before having sex with me. It’s just like that. Like having kids, you know? I really want to have kids and that’s going to be; I guess it could be an issue. I guess maybe it couldn’t. I don’t know though.

If you are positive, you’re probably a little more healthier than being: “oh, I’m going to get sick and this is never going to go away or anything.

I’d hide them (medications) like in my socks or I’d hide them in my pockets or I wouldn’t take them because I, you know, I was a lot younger. I didn’t realize how much they do help me and how much they’re probably going to help me in the future.

Some of my friends or some people were like. They are drinking pop and they’re like “oh no. you might get AIDS from that…” I’m like looking at them like ‘oh my God, you have no idea!"

“It’s nice to go to camp because like I don’t tell any of my friends here that I have HIV. They don’t know anything of that, right. I’m just a regular kid, right…

It’s not like you have a third eye or something… I can hug you, I can kiss you; you’re not going to get it. People think that way. They’re just way too paranoid and way too sketchy about everything. I don’t think that people need to be educated in the way of what AIDS and HIV is, because obviously people know what it is; they need to know how people are with it.

If you are positive, you’re probably a little more healthier than being: “oh, I’m going to get sick and this is never going to go away or anything.

Some of my friends or some people were like. They are drinking pop and they’re like “oh no. you might get AIDS from that…” I’m like looking at them like ‘oh my God, you have no idea!”

“It’s nice to go to camp because like I don’t tell any of my friends here that I have HIV. They don’t know anything of that, right. I’m just a regular kid, right…”

I’d hide them (medications) like in my socks or I’d hide them in my pockets or I wouldn’t take them because I, you know, I was a lot younger. I didn’t realize how much they do help me and how much they’re probably going to help me in the future…

“HIV POSITIVE KIDS“

I’d actually like to have a friend with HIV, like, like somebody my own age or maybe like a little bit younger or a little bit older just because, then, you can relate to the same things, you’d be like: “oh yeah, I remember taking that drug and getting that.” Like you just have, like a lot, like something that’s really big in your life that’s in common with them. So yeah, I think that would be a good idea.
What can make things better for HIV-positive kids in BC?
The adults and kids in this study felt that different people can help make changes to create a better situation for HIV-positive kids in BC. These people include HIV-positive kids themselves, family members, professionals, and people in government. Some of these changes are easier to make than others and people in the study brought up that sometimes there and problems like there’s not enough money or people to do the work. But everyone in the study had lots of interesting suggestions like programs where HIV-positive kids can hang out together in youth groups or doing fun activities together like movie nights, skateboarding, and sports. People also felt like it is important that HIV-positive kids get more support and information about things like the HIV-virus, medications, and boyfriends and girlfriends – especially as you get older. As kids with HIV, you have some great ideas and can talk to people more about your ideas and what activities and programs might be possible to make your lives better in the future.

Examples of Program Ideas

Youth group or E-group
Youth Drop-in Centre
Buddy/mentorship programs for families and kids
Education sessions to fight discrimination
Appendix D: 2007 Community Meeting HYCUP Report
Development and Application of a Pilot Intervention for Older Children and Youth with Perinatally-acquired HIV in BC

Significance: Currently, children living with perinatally-acquired HIV infection in British Columbia are approaching or have already reached adolescence. These children and their peers in other Western countries where there is access to antiretrovirals represent a unique cohort in the global epidemic as they have developed throughout their life course with HIV. In the worldwide HIV epidemic, they constitute a new population that has never before existed and an area where research and information are scarce. These children and youth face a litany of complex medical and psychosocial challenges and require specialized services as they mature.

Theoretical Approach: This action research approach is informed by the Precede-Proceed and people-centered model of health promotion for program planning and evaluation.

Purpose of the project: To develop a community health promotion intervention tailored to address various needs within a population of older children and youth with perinatally-acquired HIV in BC.

"I’m just a regular kid, right. Well, I am a regular kid but, I mean, I do have a disease.”

HYCUP Project

<table>
<thead>
<tr>
<th>Project Goals</th>
<th>Needs Assessment</th>
<th>Literature Synthesis</th>
<th>Community Consultation/Environmental Scan</th>
<th>Expert Interviews</th>
</tr>
</thead>
<tbody>
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<td>2</td>
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<td>7</td>
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</tbody>
</table>

HYCUP Research Project
University of British Columbia
LPC Rs. 435, 2206 East Mall
Vancouver, BC, Canada

Phone: 604-822-0434
Fax: 604-822-9210
needs assessment

The current consultations build on a qualitative, community-based needs assessment conducted with older HIV-infected BC children, their families, and their service providers in 2004. According to findings, education and support is needed for psychosocial issues such as sexual health, stigma, and mental health. The proposed program will aim to begin to fill the service gap which exist as the children become youth.

The study examined the children and youths’ needs as identified by various including 4 focus groups and 7 in-depth interviews with young people with perinatally-acquired HIV (n=10), their biological and foster family members (n=11), and their healthcare and community service providers (n=10). At the time of the study in 2004, their ages ranged from 9 to 16 years old.

The HIV-infected children in BC come from extremely varied family situations with some of the children living in foster care, some living in double or single-parent households, or being cared for by biological grandparents or siblings. Many of them also belong to culturally marginalized groups with a disproportionately high number of Aboriginal children. Several of the children have behavioural and/or school difficulties. Adult and child/youth participants were asked to identify major areas of need and suggest strategies for addressing the unmet needs of this population. These needs are represented above in Figure 1.

Of these various needs, participants emphasized the shared psychosocial requirements of the children such as the issues of mental health, sexual health, and social stigma. It became apparent that these children lack youth-specific, social and community programs to assist them in their adolescent transition and adult lives. As part of the study, participants collectively suggested strategies that involved providing peer support and education to the children and youth with perinatal infection as well as family support services, professional services, and educational programs to increase awareness in their communities.

The children and youth who took part in the study tended to favor programs that had recreational components and allowed them to interact with each other and have fun.

![Figure 1: Major Issues Affecting Older HIV-Infected Children](image)

"I'd actually like to have a friend with HIV... just because, then, you can relate to the same things. You'd be like, 'Oh yeah, I remember taking that drug and getting that.' Like you just have... something that's really big in your life that's in common with them."
## Literature Synthesis

**Objective**

To determine what is in the literature regarding successful program elements for HIV-infected youth.

"In the future, if... we eventually want to have sex, I'm going to have to tell her this (HIV status), cause you know, I just think that she should know before having sex with me. It's just like that. Like having kids, you know? I really want to have kids and... I guess it could be an issue. I guess maybe it couldn't. I don't know though."

**Methods**

- Literature search: A review of 8 electronic databases for articles published since 1986 was performed.
- The databases examined were: MEDLINE, AIDS/LINE, PsychINFO, CINAHL, Web of Science, ERIC, Academic Search Premier, Social Science Abstracts.
- A manual search of 21 relevant journals of the previous six months was performed.

**Search Criteria**

- Initial inclusion criteria were program models for youth with HIV.
- Any article that examined prevention programs for HIV-uninfected youth or clinical trials were excluded.
- The geographic catchment area for inclusion was North America, Australia, and Europe.

**Results**

- A total of 43 articles describing program models or issues for youth with HIV were selected for review.
- 33 programs were described in 43 articles. 3 programs that were not evaluated were excluded.
- The 10 articles that included pediatric HIV youth were also evaluated and were not excluded further.

In the literature, the importance of tailoring programs to the target population was outlined as a guiding element in program planning. The programs should be age-appropriate, flexible, medically appropriate, and client-centered.

The most inclusive program model would be a linked services, client-focused, comprehensive multidisciplinary care and support model with a peer-based component. Youth would be involved in program planning and implementation with a focus on preparing young people for independent living as adolescents and youth with a chronic illness.

According to the multisite US SPNS study, the most comprehensive program for HIV-infected youth would contain the following five elements:

- Peer-youth information development and dissemination
- Peer-youth advisory group
- Peer-youth outreach-support group
- Professional tightly linked medical and social support network
- Case/program management advocacy

The basic elements that exist in documented psychosocial programs that serve HIV-positive young people include: case management 53%, counseling 46%, outreach 42%, assessment and treatment 44%, peer involvement 37% and mental health and substance use counseling.

### Main Facilitators of Care

1. Youth/peer involvement
2. Outreach
3. Case management and linkage to services
4. Comprehensive continuum of care
5. Family involvement
6. Engagement and stabilization
7. Developmentally appropriate services

### Main Barriers to Care

1. Health system factors
2. Disclosure
3. Therapeutic factors
4. Psycho-emotional factors
5. Social factors
6. Cultural issues
7. Transportation
Community Consultations/Environmental Scan

An Environmental Scan was implemented to discover what programs currently exist for older Canadian HIV+ children, the best practices in this area, and recommended programs. Major centers for HIV Pediatric treatment and services across Canada were chosen for review. The purpose of the scan was to look across the country (predominantly outside of BC) at clinical & community programs and practices to gather an overview of current services, best practices, and recommendations for future programming for children and youth living with HIV.

Summary of Community Services

- **Camp Moomba** - a week long summer camp in BC for children across Canada infected/affected by HIV/AIDS with year-round recreational/sports programs for children infected and affected by HIV/AIDS
- **Hummingbird Kids Society** - monthly birthday parties for affected families with children infected and affected by HIV/AIDS
- **Les Enfants de Bethany** -
  - Provision of support to parents/families around stigma and disclosure
  - **Committe des Jeunes** - a youth-driven group with adult supervision that offers recreational and educational opportunities
- **Teresa Group** -
  - Provision of formula, diapers, food, clothing and other basic necessities to families
  - **Leading the Way Program** - a support group for over 30 children, youth, parents and caregivers
  - **Counselor In Training** - a program that trains older youth (16-18) to be mentors and helpers to Leading the Way kids
  - **Tutoring Program** - a program that trains older youth (18+) to go into the homes of Leading the Way kids
- **YouthCO AIDS Society & Positive Youth Outreach** - provision of peer counseling, peer support groups, drop-in programs & social activities. However, few, if any, perinatally-infected youth access these services.
- **CASI (national)** -
  - 'An HIV/AIDS youth awareness campaign, which includes posters targeting youth & sexual risk behaviors in a youth friendly way
  - 'Connecting Youth with Youth: a Guide to Youth and HIV/AIDS-related Programs and Projects Across Canada'
- **CATIE (national)** - 'Live Positive' - an online tool/resource, focused on treatment issues, for HIV positive youth

"It's nice to go to camp because like I don't tell any of my friends here that I have HIV. They don't know anything of that, right. I'm just a regular kid, right... then, when we go to camp everybody has this in common, so it's like you can just kind of feel really relaxed and just, you know, whatever, be really, really happy, know that everything's okay and everybody knows and everybody's going to support you and not sit there and feel sorry for you or change their opinion on you, kind of thing."

Where are More Resources Needed?

- employment education programs and training
- improving community awareness
- transition models
- support around managing stigma, and disclosure
- help with grief, loss and isolation
- youth friendly mental health services
- financial support for youth and youth programs
- providing peer role models
- specific services for young men, especially heterosexual men
- adherence to antiretroviral therapy support (eg. DOT)
- education and support with sexuality
- substance use prevention and treatment
- overcoming language/cultural barriers
- providing evening clinics
- positive sexual education
environmental scan: models of care in practice

Programs are Working to Support:
- adherence to HIV medication
- sexual health
- school issues
- disclosure of HIV status and mental health issues
- transition into adult programs

"I'd hide them [HIV meds] like in my socks or I'd hide them in my pockets or I wouldn't take them because, you know, I was a lot younger. I didn't realize how much they do help me and how much they're probably going to help in the future."

<table>
<thead>
<tr>
<th>addressing adherence to HIV medication</th>
<th>addressing sexual health</th>
<th>addressing school issues</th>
<th>addressing disclosure &amp; mental health issues</th>
<th>addressing transition into adult programs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Program Elements:</td>
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<tr>
<td>- bio-psychosocial model</td>
<td>- bio-psychosocial model</td>
<td>- family therapy</td>
<td>- case management</td>
<td>- case planning/management</td>
</tr>
<tr>
<td>- asset-based approach</td>
<td>- individual therapy,</td>
<td>- case management</td>
<td>- individual counseling</td>
<td>- developmental approach</td>
</tr>
<tr>
<td>- support negotiating the medical system</td>
<td>education (transmission, progression)</td>
<td>- positive youth development</td>
<td>- family therapy</td>
<td>- (gradual process)</td>
</tr>
<tr>
<td>- reward systems</td>
<td>- individual approach</td>
<td>- individual learning plans</td>
<td>- goal setting and role plays</td>
<td>- education (transmission, progression)</td>
</tr>
<tr>
<td>- multidisciplinary consensus-based decision making</td>
<td>- sexual health counseling</td>
<td>- school liaison</td>
<td>- pre and post test counseling</td>
<td>- family involvement</td>
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<tr>
<td>- electronic reminders (eg beepers)</td>
<td>- couples counseling</td>
<td>- psychometric assessments</td>
<td>- couples counseling</td>
<td>- period of shared care</td>
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<tr>
<td>- involvement of child welfare agencies</td>
<td>- case management</td>
<td>- tutoring program</td>
<td>- support groups</td>
<td>- integrated adult/child services</td>
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<td></td>
<td>- readiness assessment</td>
<td>- accessing disability support</td>
<td>- referrals to mental health teams and community counselors</td>
<td>with consistency of multidisciplinary team</td>
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<td></td>
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<td>- informal peer support</td>
<td>- involvement of adolescent medicine teams</td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td>- collaboration with adult community services</td>
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</tbody>
</table>
Suggested Funding Sources

- Canadian Institute of Health Research
- CKNW Orphan's Fund
- Ministry of Children and Family Development
- Ministry of Health
- Pharmaceutical Companies
- Private Foundations
- Provincial Health Services Authority
- Public Health Agency of Canada
- Red Cross
- United Way
- Vancouver Foundation

Program Elements that Promote Sustainability:
- strong Board of Directors
- partnerships (eg. between community & academic groups)
- effective ongoing evaluation
- good leadership
- diverse funding base
- vision, realistic goals and objectives
- communication and feedback to funders and partners
- starting small with incremental growth
- program as part of public sector as non-profit society with billable services (eg. McCreary)
- funding should ideally be part of agencies operational budget
- built-in sustainability plan
- encourage the development of social enterprise to gain business support

"[T]he future comes and whatever it throws at you, it will throw at you. Who knows? You just gotta like base things day from day because you have no idea what is going to be in the future. You can't be like, "Oh, yeah. I'm going to go to college ... and live in a mansion and have five kids and a dog and a cat. It's obviously not going to work like that at all, at all."
In-depth interviews were conducted with a total of 15 leading researchers and healthcare services providers in pediatric and adolescent HIV. The majority were university faculty members or Directors of clinical programs. Five worked primarily in research environments and 10 in clinical settings (8 adolescent and 2 pediatric/family clinics). Four were located in Canada, 7 in the US, 2 in the UK, and 2 in Australia. These experts were asked to identify core elements for programs targeting HIV-positive young people. The following are the overarching categories that emerged through the interviews.

- “The question of financing is a very fundamental aspect of the programs in that often funding is available to set up programs and put them into action but one year later when the program has been evaluated, there’s no longer money available to continue with the program. There would have to be a political willingness to sustain this type of program.”
- “Having a diverse work force, having providers who actually like teenagers and although that sounds so easy, or so obvious, it isn’t frequent, a lot of times... That they’re somehow going to be, recalcitrant, or rude, or, difficult, or, juvenile delinquents, or take too long to see.”
- “Personally, an effective program is a program that reaches its goals, clearly.... You see, it depends on how the goals are formulated. For me, the program has to make room for involvement. It is a program that results in a transformation of the person involved in it. But it has to be an overall change, to their sense of well-being, connected to their feeling of being able to function in everyday life, to their self-esteem, to their ability to enter into relationships with others.”
Appendix E: HYCUP Follow-up Research Grant Proposal
One-Page Summary of Research Proposal submitted (November, 2008) to the Canadian Institutes of Health Research Community-Based HIV Research Competition

Amount: $100,000/year X 3 years

Principal Investigators: James Frankish (UBC), Sarah Fielden (UBC), Stephanie Grant (YouthCo AIDS Society, BC)

Co-Investigators: Joshua Balson (Camp Moomba, BC), Healther Hoiness (AIDS Vancouver, BC), John Forbes (Oak Tree Clinic, BC), Jean Shoveller (UBC), Caroline Miller (Simon Fraser University, BC), Mylene Fernet (University of Quebec in Montreal, QC).


Title: Evaluating the success of a community intervention targeting HIV-infected and HIV-affected adolescents in BC: the HYCUP research partnership

Introduction: This proposal builds on previous research examining the needs of HIV-positive children and adolescents in British Columbia. Through this initial research, components of a health promotion program tailored to the unique needs of this group have been identified and explored. The process of research and building a program model for HIV-positive adolescents/youth in BC has highlighted a glaring gap in knowledge and service delivery for all adolescents born to HIV-positive parents, both HIV-infected and HIV-affected. Existing evidence on the health and wellness of children living in families affected by HIV/AIDS in Canada suggests extremely complex individual, social and cultural needs that continue to go unmet. To date, little research speaks to the characteristics or service needs of adolescents and young adults within these familial settings.

Research Summary: The proposed research will use a community-based participatory approach; involving various members of the community through all stages of the research. The proposed program will integrate the various populations of adolescent children of HIV-infected parents under an umbrella community service/intervention research model. It utilizes theoretical models and conceptual frameworks of health promotion and program planning including meaningful youth involvement. This research proposes to generate new knowledge about the lives and health of HIV-infected and HIV-affected adolescents through evaluating an interventions model delivered to those identified as high-needs and through assessing the needs of a broader population of these HIV-affected and HIV-infected young people. This research rests on a strong foundation of existing partnerships between community groups, clinical specialists, and researchers that work with HIV-infected families. It will seek to further strengthen and evaluate this community-academic partnership and to share lessons learned with other academics and
community stakeholders. It will build the research capacity of the various organizations involved as well as the young people engaged in the project coordination and management. Young people participating in the proposed support and education programs with community partners (case management and Peer Youth Conference) will benefit from comprehensive services designed to meet their needs and will participate in youth-friendly evaluation to maximize program success.

**Research Question**: What characterizes an effective community-based intervention for adolescent children (13-21 years old) of HIV-infected parents that serves to enhance their health, prevent HIV risk behaviours, and improve their quality of life?

**Objective 1**: to describe and evaluate a community based intervention directed specifically at a group of high risk adolescents.

**Objective 2**: to describe and evaluate a partnership between academic, community and clinical stakeholders.

**Objective 3**: to build young people’s capacity to meaningfully participate and benefit from research.

**Objective 4**: to provide exploratory data and information about an under-served and under-researched group to inform future programs/policies/research.

**Research Methods**: Quantitative methods will include the assessment of cross-sectional surveys and the analysis of database indicators. Qualitative methods will include in-depth interviews, field notes, and focus group using innovative youth-friendly research approaches such as visual techniques (asset mapping, photovoice, and body mapping).
Appendix F: Additional Tables
### Table 4.4: Studies including youth with perinatally-acquired HIV in programs

<table>
<thead>
<tr>
<th>First Author</th>
<th>Program goals</th>
<th>Program Settings</th>
<th># perinatal youth</th>
<th>Program Staff</th>
<th>Program Approach</th>
<th>Program Elements</th>
<th>Key Conclusions/ Lessons learned</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ellis, D</td>
<td>To increase child cooperation/responsibility with medication administration, increase parental supervision, support &amp; completion of administration of medication</td>
<td>Immunology Clinic at Children’s Hospital of Michigan</td>
<td>19 (All)</td>
<td>Multidisciplinary team including immunologist, pharmacist, SW, nurse, psychologist and patient advocate</td>
<td>Informed by the Social Ecological Theory &amp; Family Systems theory; MST is an intensive, family-centered, community-based psychotherapy approach</td>
<td>Home-based family therapy</td>
<td>Intensive home-based family therapy may be a viable alternative for the treatment of HIV-infected children with high viral loads in the absence of viral resistance, for which the most likely explanation is serious adherence difficulties; given that MST therapists carry low caseloads (4-6 families) to maintain intensive and frequent contact, it was considered more cost effective to use such resources for only the neediest families who were unlikely to respond to other services (medication re-education, outpatient psychotherapy)</td>
</tr>
<tr>
<td>Funck-Bretano, I</td>
<td>To support a group of perinatally-infected adolescents through a therapeutic process involving sharing experiences, promoting change, and goal-setting</td>
<td>Clinical</td>
<td>25 out of 30</td>
<td>2 therapists</td>
<td>Support Group</td>
<td>A 90-minute session once every six weeks for 26 months; unstructured support group with youth-directed themes</td>
<td>The peer support group had a beneficial effect on the adolescents' acceptance and perceptions of their HIV infection. Despite reluctance to talk in groups, 10 agreed to be in a group and share their difficulties with HIV-infected peers. It is possible that parent anxieties regarding their child increased the pressure on an already anxious adolescent. Despite the difficulties associated with HIV-infection, the study population developed good self-esteem</td>
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<tr>
<td>Lyon, M</td>
<td>To increase adherence to antiretroviral medications among HIV-positive youth and to involve families and peers in this effort</td>
<td>Not stated; likely hospital-based</td>
<td>2 out of 23</td>
<td>Multidisciplinary treatment team (physician, nurse practitioner, two case managers, and two mental health professionals)</td>
<td>Family-centered education</td>
<td>A 12 week program with 6 bi-weekly family and youth education sessions and 6 biweekly youth-only education sessions; include 30-minute dinner, separate 60-minute group education sessions, and 30-minute review of materials in game show format together; adherence aids (pillboxes, dummy beepers, calendars, wrist-watches with multiple alarms, gym bags)</td>
<td>It is important to: simplify the medical regimen for HIV-infected youth whenever possible; try to increase medical knowledge using a variety of developmentally appropriate methods and materials; and engage peers and family to help with adherence. Interventions need to be individualized so that they do not disrupt previously established routines that were working for the patient, nor ignore cultural differences. Providing a caring environment in which HIV-positive youths perceive that they are valued appears to be a critical but difficult-to-measure variable. Although the multiple alarm watch was rated by the youth as the most highly valued tool, forgetting remained the primary reason for missing a dose. Involving family members in a supportive environment as well as peers may be one technique to improve adherence to complicated medical schedules</td>
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<tr>
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<tr>
<td>Naar-King, S</td>
<td>To target more than one risk behavior but tailored to the needs of the individual youth</td>
<td>clinical</td>
<td>9% (Approx 5 out of 51)</td>
<td>Counselors (grad students and post-doc); HIV specialists, nurse, social worker, psychologist, case manager, peer advocate</td>
<td>Motivational interviewing (incorporating the transtheoretical model)</td>
<td>counselor training sessions; four 60-minute client sessions with counselors</td>
<td>Research staff dedicated to conducting home visits and lost-to-follow-up outreach might boost retention. Studies could be improved by scheduling the first session immediately after data collection or meeting the therapist prior to the intervention to increase comfort and trust. Healthy Choices was effective in improving health outcomes and condom use and may be effective in reducing substance abuse. Future studies with larger samples may look at whether drops in viral load are associated with drops in other behaviors and/or stress</td>
</tr>
<tr>
<td>Weglarz, M</td>
<td>To provide expert comprehensive care for children with HIV and their families</td>
<td>home and university-based treatment center</td>
<td>1 (All in case study)</td>
<td>Multidisciplinary team: pediatric and adult HIV specialists (with adolescent care referrals); physicians, nurses (including case managers); psychologists, social workers, researchers, outreach workers, nutritionist, playroom therapist)</td>
<td>Comprehensive care model informed by Family Systems Theory</td>
<td>home visits, ambulatory care, nurse case management and referrals, primary care and monitoring, skill-building and education (HIV, meds, etc), adherence tools</td>
<td>Empowering the family is an effective strategy for improving adherence and opening communication with the child and family enables nurses to provide family support. Home visits encourage families to include healthcare providers as part of the family support network. Using a family-centered approach to care enhances the partnership between nurses, children, and their families</td>
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<tr>
<td>Woods, E</td>
<td>To provide comprehensive linked services through a network of agencies to provide a range of services to connect HIV-positive, at-risk, and homeless youth with adolescent-specific HIV VCT primary care and HIV services</td>
<td>Health Care, Store Front clinic, Mobile Van, HIV C&amp;T, Drop in, off-site medical care</td>
<td>3 out of 46 HIV+ (1301 youth total)</td>
<td>Principal Investigator, Youth and Adult Advisory boards, planning board, Clinical Director, Mental Health Director, Case Management Team, Project Co-ord, Stats, RA, Eval, Peer Coord, Outreach and Services co-ord, Peer leaders. 4FT, 6-8 PT</td>
<td>Linked Services Model of Care</td>
<td>Street Outreach, 2 drop in centers, storefront clinic, 2 multiservice sites serving homeless and sex trade involved youth; outreach and risk reduction counseling through professional and adult-supervised peer staff, access to appropriate HIV counseling and testing support services, life management counseling; health status screening and services needs assessment; client-focused comprehensive multidisciplinary care and support, follow-up outreach to ensure continuum of care, integrated care and communication among providers in the Metro Boston area</td>
<td>Mental health services need to be incorporated into medical visits. Barriers to expanding care included lack of funding, transportation, and youth being unaware of services. There is a need for HIV-specific services, access to clinical trials, mental health and substance abuse services, vocational training, housing and dental care. Outreach and targeted counseling continue to be important components for case identification though most HIV-positive youth in care have been referred from local agencies. Barriers to testing and cultural norms around testing need to be reassessed so that highest risk youth will access HIV VCT</td>
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<td>First Author</td>
<td>Program goals</td>
<td>Program Settings</td>
<td># perinatal youth</td>
<td>Program Staff</td>
<td>Program Approach</td>
<td>Program Elements</td>
<td>Key Conclusions/ Lessons learned</td>
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<td>Woods, E</td>
<td>To provide a model of collaborative care and outreach to meet the needs of youth in Boston. The network linked nine core agencies and institutions, including three teaching hospitals</td>
<td>Clinical care sites and community-based organizations</td>
<td>3 out of 26 HIV+ (1044 youth total)</td>
<td>Professional and adult supervised peer staff; outreach and services coordinator, nurse case manager, primary care staff</td>
<td>Linked Services Model of Care</td>
<td>Outreach and risk reduction counseling through professional and adult-supervised peer staff, access to appropriate HIV counseling and testing support services, life management counseling; health status screening and services needs assessment; client-focused comprehensive multidisciplinary care and support, follow-up outreach to ensure continuum of care, integrated care and communication among providers in the Metro Boston area</td>
<td>Through this network of care, hard to reach populations were able to access program medical services. The impact of outreach and case management on engagement and retention of youth in care should be studied further. Services for adolescents and young adults need to include reproductive services, support for parenting, substance abuse services, and services which are comfortable for LGBTQ, street and homeless young people. Data for model programs are essential for comparing programs and developing national policies</td>
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