

# Promising Models of Programming for Youth Living with HIV

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Report prepared by the Saskatchewan Prevention Institute

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#### 1. Introduction

Saskatchewan has seen a substantial increase in the number of new cases of human immunodeficiency virus (HIV) since 2003. In 2011, Saskatchewan had the highest rates of new cases of HIV in Canada at more than twice the national average (19.6 vs. 7.6/100 000) (Public Health Agency of Canada [PHAC], 2012). Currently in Saskatchewan, women of childbearing age (ages 15 to 39 years) are one of the groups with the largest increases in HIV infection rates, with the average age of new adult female cases in 2011 being 34.2 years (Saskatchewan Ministry of Health, 2012). Therefore, it can be expected that there will also be a rise in the number of infants who are perinatally exposed to the virus. According to PHAC (2011), 125 infants in Saskatchewan were perinatally exposed to HIV between 1984 and 2010. Of these, 14 became infected, with one dying of AIDS (acquired immunodeficiency virus), and one dying of other causes.

Antiretroviral therapy (ART) and other advancements in care have resulted in HIV being reclassified from a fatal disease to a chronic medical condition (Das, Mukherjee, Lodha, & Vatsa, 2010; Davies, Bachanas, & McDaniel, 2002; Garvie et al., 2009; Hazra, Sibery, & Mofenson, 2010; Paul et al., 2009; Rao et al., 2007). These advances have also led to improved prevention of mother-to-child transmission (MTCT) of HIV and, consequently, fewer children being born with HIV (Canadian AIDS Treatment Information Exchange [CATIE], 2007). For children who are born with HIV, ART has resulted in decreased mortality and morbidity; meaning that individuals born with HIV live to much older ages and experience a less symptomatic disease course (Das et al., 2010; Mellins et al., 2002).

While children living with HIV currently face a less symptomatic disease course, they continue to face numerous challenges that can impact their overall health and quality of life. Specifically, research has shown that in addition to the direct damage HIV has on physical health, HIV can affect children cognitively, developmentally, emotionally, psychologically, and educationally (Davies et al., 2002; Garvie et al., 2009; Malee et al., 2011; Paul et al., 2009; Wachsler-Felder & Golden, 2002). Unfortunately, children living with HIV also often face problems related to the social determinants of health, including poverty, poor nutrition, social instability, a high incidence of familial substance use, death of family members, and issues related to stigma and discrimination (Brown, Lourie, & Pao, 2000; Elliott-DeSorbo, Martin, & Wolters, 2009; Forsyth, 2003; Naar-King et al., 2006; Simoni et al., 2007; Williams et al., 2006). Each of these factors can play a confounding role in pediatric HIV treatment outcomes, either by mitigating or increasing the adverse impacts of HIV.

These factors may also disrupt many of the social support systems that youth depend on for optimal development (Steele, Nelson, & Cole, 2007). Research has shown that youth living with HIV have low involvement in activities, fewer social interactions, more absences from school, and fewer positive emotions (Steele et al., 2007). In contrast, social and community support services have been associated with improved treatment adherence, improved psychological outcomes, and improved overall functioning (Das et al., 2010; Gaughan et al., 2004; Goldstein & Morewitz, 2011; Sacajiu, Raveis, & Selwyn, 2009; Panel on Antiretroviral Therapy and Medical Management of HIV-Infected Children, 2011). Taken together, these findings highlight the importance of support programs and

services aimed at youth, in addition to medical treatment, for improved health outcomes of youth living with HIV.<sup>1</sup>

#### 1.1 Current Report

Recognizing the importance of such services and programs for youth living with HIV, the Saskatchewan Prevention Institute conducted a search for Saskatchewan-based support services for youth living with HIV, as well as a search for promising support programs in North America. Such a search allows for the identification of existing, effective programs and services, while also providing information to others who may wish to develop such programs. In order to identify Saskatchewan-based support programs and services specifically designed for youth living with HIV, an online search was conducted and contact was made with existing AIDS service organizations. (See Appendix A for a list of the organizations that were contacted.) The North American programs and services included in the current report were identified through an online search. The overall purpose of the current report was to identify any youth-specific HIV support programs and services currently available in Saskatchewan, while also identifying promising programs in other parts of North America. Programs with a purely medical focus (e.g., those based in hospitals, with no specific additional support programs/services identified) were not included in the current report. As well, programs that are geared toward adults living with HIV, but include youth in their clientele, were not included.

#### 2. Saskatchewan-Based Programs and Services for Youth

It is important to first note that many, if not all, of the existing Saskatchewan-based services and programs for people living with HIV are willing to serve youth (see Appendix A). That being said, no support programs or services designed specifically for Saskatchewan youth living with HIV were identified. Instead, it appears that youth living with perinatally acquired HIV typically access services through their pediatric infectious diseases specialists. These specialists, while being responsible for the youth's HIV-related medical care, are also able to refer them for other support services and care as necessary. Youth with behaviourally acquired HIV may receive care from either a pediatric or an adult infectious diseases specialist, depending on their age at infection. As many AIDS service organizations provide services and programs designed for people with high risk lifestyles (e.g., substance use, sex work), the programs offered by these organizations may be beneficial for youth living with behaviourally acquired HIV. Saskatchewan youth living with HIV also have the opportunity to access certain programs and services from around North America (e.g., online support services, summer camps, and conferences).

<sup>&</sup>lt;sup>1</sup> Please refer to a previously completed literature review by the Saskatchewan Prevention Institute titled "Pediatric Care and Support for Children Living with HIV in Saskatchewan" for more in-depth information about pediatric medical treatment for HIV (ART efficacy, drug resistance, side effects); treatment adherence; physical, cognitive, and psychological effects of HIV; the impact of stigma on treatment and care; disclosure of HIV status; nutrition; and school issues.

### 3. North American Programs and Services for Youth

In other parts of Canada and the United States, commonly in areas with larger populations, youth-specific HIV programs and services do exist. Even in these areas, however, programs and services focused on HIV education and prevention in youth far outnumber support programs and services for youth already living with HIV. Similar to the Saskatchewan-based HIV programming, many of the North American support programs available for adults are willing to serve youth. While these programs are likely able to refer youth for appropriate additional care and support, they are not designed with youth-specific needs in mind. The following section includes descriptions of the youth-specific support programs and services that were identified in Canada and the United States. Information about the target populations, program descriptions, and services provided is also summarised in chart-form in Appendices B through D, along with the contact information for each organization.

#### 3.1 Canadian Programs and Services

According to CATIE's Western Regional Health Education Coordinator, Melissa Egan (2007), finding supports for youth living with HIV in Canada is a challenge. Canada's most populous provinces (British Columbia, Ontario, and Quebec) do have some youth-specific programming. The most well-known service provider for youth and families living with and affected by HIV in Canada is The Teresa Group based in Toronto, Ontario. This AIDS service organization has been in existence since 1990, and focuses specifically on the needs of families affected by HIV. The program provides welcome-home baby supplies, free formula, diapers, a children's clothing bank, assistance with public transit fares, backpacks of school supplies, packed lunches for school, and tutoring for students in grades 2 to 12. Other youth-specific services offered by the Teresa Group include the "Leading the Way" support group, which provides youth aged 5 to 18 a safe place to discuss the issues and challenges they face. This support group runs for 9 weeks at a time, twice each year. Finally, "Graffiti as Therapy" is a Teresa Group program in which youth get to express their feelings in an artistic manner.

The Oak Tree Clinic located at the Children's and Women's Health Centre of BC in Vancouver, British Columbia is another example of family-centred care for HIV. This clinic provides HIV care and treatment to children, pregnant women, and women and their partners. In addition to medical care, the Oak Tree Clinic provides education and advocacy. Youth are able to access pediatric, adult, obstetric/gynecological care, as well as addictions counsellors, social workers, outreach workers, and researchers. By providing such a variety of care in one place, the Oak Tree Clinic improves access to specialized care in a safe environment.

Toronto and Vancouver have peer-based programs for youth living with HIV. In Toronto, Positive Youth Outreach is part of the AIDS Committee of Toronto (ACT). Positive Youth Outreach is designed for youth living with HIV aged 16 to 29, and is the longest running peer-based HIV support program in Canada. It provides outreach, support, advocacy, referrals, as well as education, personal development opportunities, and peer support. The stated goal of the

program is to equip young people living with HIV with the practical tools needed to make informed decisions and develop leadership skills. There are weekly support and discussion groups, drop-in support, and community outreach programs. Participants in Positive Youth Outreach also offer learning workshops for other youth living with or affected by HIV. These workshops include information about living with HIV, HIV treatment, nutrition, HIV disclosure, harm reduction, and healthy relationships. In addition to the services provided through Positive Youth Outreach, youth living with HIV can also access services provided by ACT, including case management, information sessions, counselling, employment assistance, and meals.

In Vancouver, YouthCO provides services to youth living with HIV and/or hepatitis C, between the ages of 15 and 29. YouthCO is a peer driven organization that acts as a resource and facilitator for educational initiatives and support services throughout British Columbia. All of the staff members are youth, and some have lived experience with HIV and hepatitis C. YouthCO provides support (including support groups), counselling, advocacy, education, needle exchange, referrals, meals, and outreach. YouthCO's Positive Youth Support Program offers confidential support, one-to-one peer counselling, and group support. YouthCO offers leadership training, and its Peer Facilitation Team delivers peer-to-peer workshops and training. YouthCO's educational program also includes resource development, a theatre group, and videos. All of this programming involves youth providing support and education/prevention services to other youth. Specific sub-programs are also offered for gay male youth ("The Social") and for young women ("The Women's Group").

Although organizations such as these are not available in all areas in Canada, youth from across the country are able to access HIV-specific summer camps. These camps offer youth living with HIV the chance to be accepted, find friendship with others facing similar challenges, and develop knowledge and new skills. These camps include many of the traditional camp activities (e.g., swimming, canoeing, campfires, arts and crafts, and sports activities), while also providing care and support around HIV. Crucial, life-long supports are often created through these camp experiences. Camp Moomba is the most well-known and longest running camp in Canada for youth living with and affected by HIV (aged 6 to 17). It is run by the Western Canadian Pediatric AIDS Society, and takes place every summer in British Columbia. Three other camps were identified in Canada: Camp Laurel Canada, Camp Positive Families, and Camp Wendake. While Camp Laurel Canada focuses on children living in the Greater Toronto Area, the other three camps serve children from across Canada. Camp Wendake serves people living with HIV, including children, youth, and their caregivers. Camp Positive Families, which provides a camp experience for women along with their children, also includes workshops on HIV medications, treatment adherence, and disclosure. More detailed information about these summer camps can be found in Appendix C.

#### 3.2 American Programs and Services

There are many American-based programs that offer services to youth but are not specifically designed for youth. For example, there are family-focused programs that provide services either directly or indirectly to youth (e.g., STABLE Families, see <a href="http://metroteenaids.org/site/stable-families/">http://metroteenaids.org/site/stable-families/</a>). Many hospitals also house pediatric and adolescent HIV/AIDS programs. For example, the St. Christopher's Hospital for Sick Children in Philadelphia, PA provides primary and specialty care to pediatric and adolescent patients living with HIV (see <a href="http://www.stchristophershospital/pediatric-specialties-programs/specialties/29">http://wetroteenaids.org/site/stable-families/</a>). Along with medical care, hospital-based HIV programs typically include case management, mental health services, and referrals to other support organizations. For the purposes of the current report, however, the programs included below and in Appendix D are confined to those that provide support services specifically designed for youth and provide more than medical care and information resources.

Compared to Canada, the United States has more support programs and services designed specifically for youth living with HIV.<sup>2</sup> A number of these programs exist in California. One such program is the Bay Area Positives (BAY Positives), located in San Francisco. This program is peer-driven and is designed for youth living with HIV, aged 26 and under. A number of services are offered including youth and family counselling, support groups, prevention case management, advocacy, referral services, a drop-in centre, social activities, and weekend intensive training and education events. BAY Positives also offers a speaker's bureau as well as HIV and sexually transmitted infection (STI) prevention workshops.

The other programs based in California serve a wider age range of clients. For example, the Laurel Foundation in Pasadena provides education and support programs to children, youth, and families living with or affected by HIV. In addition to summer camps and a number of wilderness programs throughout the year, the Laurel Foundation provides a counsellor-in-training program, mentorship programs, and life enhancement workshops. The Laurel Foundation has also recently begun offering online facilitated video support groups for children and youth living with HIV. The video support group is run through "Go To Meeting," which allows for video conferencing from the comfort of the youth's own homes. This approach has received very positive feedback from the participants, parents, and social workers. All of the programs provided by the Laurel Foundation strive to contribute to the development of each youth's self-esteem, self-awareness, and self-fulfillment, in order to improve his/her overall quality of life.

The Mother, Child, and Adolescent HIV Program at the University of California, San Diego (UCSD) provides comprehensive, family-centred care to children, youth, and women. In addition to medical care, this program provides individual and family counselling, case management, peer

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<sup>&</sup>lt;sup>2</sup> There are also a number of summer camps available throughout the United States for youth living with and affected by HIV. Please refer to <a href="www.mysummercamps.com/camps/Special\_Needs\_Camps/HIV">www.mysummercamps.com/camps/Special\_Needs\_Camps/HIV</a> and <a href="AIDS">AIDS</a> or <a href="www.thebody.com/index/treat/camps.html">www.thebody.com/index/treat/camps.html</a> for a complete listing of these camps.

advocacy, an art therapy group, and support groups. Support groups are offered for families affected by HIV, youth living with or affected by HIV (aged 15 to 17), and young adults living with HIV (aged 18 to 24). The Youth Council run by this program is a peer advocacy group that speaks out for young people living with or at risk of HIV. The Youth Council also helps connect other youth to the services they need to stay as healthy as possible. The Mother, Child, and Adolescent HIV Program also offers two transition programs: one for children moving from pediatric to adolescent care (ages 12 to 14 years), and a second for those moving from adolescent to adult care. The adolescent care team provides services for youth up to 25 years of age, until they have successfully transitioned to adult care. Finally, this program also offers services specifically designed to support GLBTQQ (gay, lesbian, bi-sexual, transgender, queer, and questioning) youth living with HIV.

Project Kindle is also based in California and serves children, youth, and families living with and affected by HIV/AIDS. The Project provides two week-long summer camping programs, as well as mini-camping sessions throughout the year. In addition to these educational camping experiences, Project Kindle provides year-round support, HIV education and awareness, mentorship opportunities, and a post high school scholarship fund. SPEAK OUT (Sharing Personal Experiences and Knowledge: Our Unique Truths) is the Project's peer-to-peer speaker's bureau. The speaker's bureau was developed out of the program youth's desires to share their stories with the general public, especially with other youth. The stated goals of the speaker's bureau are to reduce stigma and raise awareness about HIV. The youth speakers, who are between the ages of 7 and 17, educate others about what it is like to live with HIV, and how to make healthy choices to protect themselves and others. Another way Project Kindle enables youth living with HIV to educate others is through their "I Know" website (iknowhiv.org). This website is a peer-to-peer social network campaign which shares general information about HIV and where to get tested, as well as videotaped stories and twitter messages from youth living with HIV. Finally, Project Kindle offers life skills retreats, where youth aged 16 to 21 are provided with workshops and resources focused on helping them transition to adulthood. The topics covered include financial management, applying for college, choosing a career, stress management, communication skills, and securing medical care after age 18.

Similar to the UCSD Mother, Child, and Adolescent HIV Program, the Montefiore Medical Center in Bronx, New York offers a comprehensive care and support program for youth living with HIV, aged 13 to 21. This program is called the Adolescent AIDS Program and was the first adolescent-specific HIV/AIDS program in the United States. It provides comprehensive medical and clinical care, as well as counselling, support groups, retreats, and recreational outings. Specialized ongoing support care is also provided for GLBTQQ youth living with HIV. The Adolescent AIDS Program also offers educational resources focused on HIV and youth, and provides opportunities for youth to participate in research that is applicable to them (e.g., HIV medication clinical trials, medical and psychosocial issues research). This program also hosts a Youth Advisory Board, which provides guidance about the creation of resources and the services and supports offered by the program. This program also has a transitioning group, which

collaborates with the Montefiore Adult HIV Program in order to prepare youth for adult HIV care. Finally, the Adolescent AIDS Program has a Peer Education Program that trains youth living with HIV, aged 18 to 24, to become community outreach workers.

The Family Ties Project, through the Consortium for Child Welfare in Washington, also provides opportunities for youth development. This project is designed for families living with and affected by HIV/AIDS, but also has programs specific to youth. Their Youth Development Program provides enrichment activities and youth leadership training. The Family Ties Project also provides child and youth case management, education, reproductive health services, counselling, and advocacy for those living with and affected by HIV/AIDS. These services can be provided at home, at school, or in other settings as determined by the individual youth.

The final youth-specific HIV support program identified in the United States is the Boston HAPPENS (HIV Adolescent Provider and Peer Education Network for Services) Program run through the Boston Children's Hospital. This Program is designed for youth aged 12 to 24 years, living with or at risk of HIV. In addition to complete medical care (including primary care, gynecological care, HIV care, full checkups), HAPPENS provides case management, referrals, and individual and group therapy. This program also provides preconception planning and birth control, as well as access to HIV clinical trials.

#### 3.3 Other Resources Available Online

#### 3.3.1 Online Resources for Youth

In addition to programs that youth can physically access, there are a number of support and information resources available online. These online resources may be particularly helpful for youth who may not be able or willing to access the service organizations listed above. For example, the AVERT website contains a section called "HIV Positive Life" (<a href="www.avert.org/hiv-positive-life.htm">www.avert.org/hiv-positive-life.htm</a>), which provides information specific to young people living with HIV. This section of the website states that its purpose is to help youth understand what living with HIV means and how to live positively ("being happy, healthy, and confident about living with HIV"). Topics covered include staying healthy, sex and relationships, and dealing with other people's attitudes about HIV. The website also provides information relevant to friends and family members of youth living with HIV.

The Hospital for Sick Children in Toronto also provides online information useful for youth living with HIV and for their care providers. The information on this site is particularly focused on helping youth successfully transition to adult care and their "Positively Good 2 Go" program (<a href="http://www.sickkids.ca/Go-Positive/index.html">http://www.sickkids.ca/Go-Positive/index.html</a>). This program provides information on HIV basics, sexual health (disclosure, safer sex, contraceptives, and STIs), medications, substance use, adult clinic options, and links to other helpful websites and resources. The website also provides some specific transition tools including a readiness checklist, a MyHealth Passport (a wallet-sized card listing medical conditions and medical history), a transition booklet, a transition timeline, and information to make the first adult

appointment easier. Most of this information is provided though the hospital's "Good to Go Transition Program" (see <a href="http://www.sickkids.ca/good2go/">http://www.sickkids.ca/good2go/</a>), which is a transition program for all children living with a chronic illness. Therefore, a lot of the information is not specific to living with HIV. That being said, the "Good to Go Transition Program" offers career clinics and supports and information about attending post-secondary education, all of which can be accessed by youth living with HIV.

#### 3.3.2 Online Resources for Healthcare Providers and Other Supports

Three other websites provide training and tools for healthcare providers who work with youth living with HIV. The first is <a href="http://www.hivcareforyouth.org/">http://www.hivcareforyouth.org/</a>. This site provides a series of online training modules called "Treating Adolescents with HIV: Tools for Building Skills in Cultural Competence, Clinical Care, and Support." The modules cover a number of topics including best practices in youth care, psychosocial issues, antiretroviral treatment and adherence, transitioning to adult care, and HIV transmission prevention. The second online tool is called "Adolescent HIV Care and Treatment: A Training Curriculum for Health Workers" (<a href="http://icap.columbia.edu/resources/detail/adolescent-hiv-care-and-treatment">http://icap.columbia.edu/resources/detail/adolescent-hiv-care-and-treatment</a>). This curriculum was designed by the Mailman School of Public Health at Columbia University. The stated goal is "to empower multidisciplinary health workers to have the confidence and skills to provide comprehensive, youth-friendly HIV services that support adolescents' healthy development, psychosocial well-being, retention, adherence, sexual and reproductive health, and eventual transition to adult HIV services." As such, the curriculum covers each of these topic areas.

The final online curriculum tool identified through the online search is provided by the Family Ties Project (see <a href="www.familytiesproject.org/Documents/GroupCurricukum.pdf">www.familytiesproject.org/Documents/GroupCurricukum.pdf</a>). This training tool was designed specifically for people wanting to start a support group for those living with HIV, in order to help insure the group's success. Curricula are provided for children living with HIV, youth living with HIV, and HIV-affected children and their caregivers. Each group curricula contains the following sections: membership definitions, membership screening criteria and processes, group time, group purpose, goals, evaluation methods, group rules, materials and activities, and session-by-session group outlines. The creators of the curricula recommend that group leaders review and revise the materials to meet the needs of the group and based on the available resources in the group's area.

#### 4. Discussion and Recommendations

The development of most of the currently available North American support programs followed the identification of a clear need for youth-specific HIV support services. In the case of some programs, like Toronto's Positive Youth Outreach and San Francisco's BAY Positives, youth living with HIV created support programs for themselves and other youth facing similar challenges. It also appears that the existing youth HIV support programs, instead of relying on other programs for guidance,

tend to create their program and service content dependent on the immediate needs of the clients they serve. Some programs, like the Adolescent AIDS Program in New York, have a Youth Advisory Committee that guides the program content.

While the currently available support programs offer different types of services, they all stress the importance of creating feelings of safety, acceptance, and belonging. HIV can be an isolating illness because of the associated negative social stigma and discrimination, along with the potential illness or death of a parent (Elliott-DeSorbo et al., 2009). Many of the existing support programs are designed to combat this isolation by helping youth build social support systems with peers and adult role models. At the same time, many of these programs focus on building important life skills and preparing youth to deal with the many challenges they will potentially face (e.g., disclosure, sexual relationships, and transitioning to adult care).

These programs also recommend that in order for a support program to best serve the needs of youth living with HIV, they need to address as many of the issues associated with HIV as possible (e.g., medical, social, psychological, academic). It is important for those designing support programs and services for youth to be cognizant of the characteristics of adolescence as a developmental stage. Henry-Reid, Wiener, and Garcia (2009) state that adolescence is a time of testing limits, marked by risk taking, struggles for independence, experimenting with adult behaviours (including sex), impulsivity, and a sense of invulnerability. While the programs and services included in the current report did not differentiate between youth who were infected with HIV perinatally and those who were infected behaviourally, it is possible that different needs may exist between these two groups – a fact that may need to be considered when designing support services. Taken together, there are a number of factors that programs working with youth living with HIV will need to consider, along with the importance of education and support for youth as they move through the adolescent developmental stage. Such support and education are important for youth living with HIV in order to maintain their own health, as well as to prevent the transmission of HIV to others.

#### 5. Conclusions

Despite the current lack of youth-specific HIV support programs and services in Saskatchewan, there are a number of promising programs and training tools available around North America that provide insight and ideas for supporting youth living with HIV or at risk of HIV infection in Saskatchewan. Currently the numbers of youth living with HIV in Saskatchewan is relatively low and the population is geographically dispersed compared to high density locations like Vancouver or Toronto. Although this fact may make the idea of youth-specific support programs seem less practical or efficient, the situation is changing. Due to the high number of new HIV infections in Saskatchewan, including new infections in youth and young adults, and due to the positive impact of support programs on youth's overall health outcomes, such programs have the potential to be an important part of the care provided to youth living with and affected by HIV.

Appropriate HIV care for youth involves more than clinical and medical care. Research has shown that support programs and services are also needed in order to insure the best health outcomes possible (Das et al., 2010). According to Brown et al. (2000) and Cohen et al. (2012), an ideal treatment model for children living with HIV would be the integration of medical, psychosocial, and social services by both primary clinicians and community-based outreach staff. Youth-friendly, comprehensive care and support are key to the health outcomes of these youth.

High HIV infection rates in Saskatchewan may also warrant the creation of youth-specific HIV prevention programs, in order to reduce the number of new HIV infections in youth. The current online search revealed a number of programs that are focused solely on the prevention of HIV infection in youth. The Centers for Disease Control and Prevention (CDC) provides a comprehensive list of evidence-based behavioural interventions for reducing the likelihood of HIV risk behaviours in youth (see <a href="www.dcd.gov/hiv/prevention/research/compendium/rr/index.html">www.dcd.gov/hiv/prevention/research/compendium/rr/index.html</a>). This site lists best-evidence and good-evidence intervention programs, along with providing program descriptions, the program goals, the target population, and the theoretical basis of the program. Finally, the site provides information about the evaluation of the programs.

Another important service that may be useful for Saskatchewan youth is the development of youth-friendly testing sites. This is becoming particularly common in the United States. According to the CDC (2012), many youth do not know they are infected, putting themselves at risk of poor health outcomes, while putting others at risk of HIV infection. Young men have been found to be less likely to be tested than young women (CDC, 2012), meaning that testing initiatives may want to focus particularly on this group.

Saskatchewan has the highest rate of new HIV infections in Canada. Therefore, the number of youth affected by and infected with HIV will likely increase in the coming years. This makes the creation of HIV prevention programs and testing programs that target youth vital for the prevention of new HIV infections and HIV transmission. It also makes the creation of youth-specific support programs and services important to consider. Based on the current review of existing support programs and services for youth living with HIV, it appears important that the content of such programs reflects the needs of the youth and is created in such a way that youth can build supportive relationships, both with other youth and with adults. If the number of youth living with HIV is not high enough in any one location to warrant the creation of physical support spaces, the creation of Saskatchewan-specific online support services and tools may be something to be considered.

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## Appendix A. Saskatchewan-Based Organizations Contacted for Information

#### **Prince Albert**

**601 North Outreach** 

101-15<sup>th</sup> Street East

Prince Albert, SK S6V 1G1

#### **Sexual Health Clinic/Access Place**

101-15<sup>th</sup> Street East

Prince Albert, SK S6V 1G1

Tel: (306) 765-6540

#### Regina

**AIDS Programs South Saskatchewan (APSS)** 

2911 5<sup>th</sup> Avenue Regina, SK S4T 0L4

Tel: (306) 924-8420

#### **All Nations Hope AIDS Network (ANHAN)**

2735 5<sup>th</sup> Avenue

Regina, SK S4T 0L2

Tel: (306) 924-8424

#### Saskatoon

**AIDS Saskatoon** 

1143 Avenue F North Saskatoon, SK S7L 1X1

Tel: (306) 242-5005

**STC Health Centre** (formerly known as SHARP)

1514 20<sup>th</sup> Street West Saskatoon, SK S7M 0Z6

Tel: (306) 956-0340

#### Persons Living With AIDS (PLWA) Network

127C Avenue B North Saskatoon, SK S7M 1M2

Tel: (306) 373-7766

#### **Yorkton**

**601 East Outreach** 

130-345 Broadway Street West

Yorkton, SK S3N 0N8

Tel: (306) 783-1722

## **Appendix B: Canadian Programs for Youth Living with HIV**

| Canadian Programs   | Target Population and Program Description  | Services Provided  |
|---|--|--|
| Oak Tree Clinic http://www.bcwomens.ca/Se rvices/HealthServices/OakTre eClinic/default.htm BC Women's Hospital and Health Centre E600-B 4500 Oak Street Vancouver, BC V6H 3N1 Tel: (604) 875-2212 | Women and children living with HIV/AIDS  Improves access to specialized care in a safe environment   | <ul> <li>Includes adult, pediatric, and obstetric/<br/>gynecological care</li> <li>Education and advocacy</li> <li>In addition to medical care professionals, care<br/>team includes addictions counsellors, social<br/>workers, outreach workers, and researchers</li> </ul>  |
| Positive Youth Outreach www.positiveyouth.com AIDS Committee of Toronto (ACT) 399 Church Street Toronto, ON M5B 2J6 Tel: (416) 340-8484 ext. 265 or ext.281 Email: pyo@actoronto.org              | Youth living with HIV, aged 16 to 29  A peer-based program that empowers, supports, and affirms the lives of young people under 30 living with HIV.                          | <ul> <li>Outreach, support, and advocacy</li> <li>Education, skills development, and leadership development opportunities</li> <li>Peer support</li> <li>Groups offered:         <ul> <li>Weekly Social Support: social support activities</li> <li>Weekly Discussion Group: Structured peer discussion support group</li> <li>Community Learning Series: learning workshops on a variety of topics</li> <li>Connecting You to Services: connects youth to other services in the community</li> </ul> </li> <li>Other services provided through ACT: case management, community health forums, counselling, weekly meals, employment education and assistance, other informational clinics and groups</li> </ul> |
| The Teresa Group www.teresagroup.ca/ 124 Merton Street, Suite 104 Toronto, ON M4S 2Z2 Tel: (416) 596-770 Email: info@teresagroup.ca   | Children affected by HIV/AIDS and their families  Provides a broad range of compassionate frontline services to hundreds of local children and families affected by HIV/AIDS | <ul> <li>Individual and family counselling</li> <li>Groups offered:         <ul> <li>Family Support Program: offers practical assistance to families having difficulty providing for their children (Kids Lunch Pack Program, Back to School Program, Get Ready for Winter Program, TTC Token, Emergency Assistance, Welcome Home Baby, diapers, baby formula, clothing bank, and birthday presents)</li> <li>Tutoring Program: one-on-one or small group tutoring for students in grades 2-12</li> <li>Leading the Way: support group for children ages 5 to 18, for 9 weeks at a time</li> <li>Graffiti as Therapy: forum for youth to express their feelings in an artistic manner</li> </ul> </li> </ul>     |

## **Appendix B continued**

| YouthCO (HIV and Hep C  | Youth living with HIV, aged 15    | - Support and advocacy   |
|-------------------------|-----------------------------------|--|
| Community Outreach)     | to 29                             | <ul> <li>Educational programs and training</li> </ul>          |
| http://youthco.org      |                                   | <ul> <li>One-to-one peer counselling and group</li> </ul>      |
| #205-568 Seymour        | A peer-driven organization that   | support  |
| Vancouver, BC V6B 3J5   | addresses youth issues            | - Referrals to community organizations and                     |
| Tel: (604) 668-1441     | concerning HIV/AIDS by acting     | appointment accompaniments                                     |
| Email: info@youthco.org | as a resource and facilitator for | - Meals, Internet access, art supplies                         |
|                         | educational initiatives and       | - Needle exchange  |
|                         | support services throughout       | - Groups offered:  |
|                         | British Columbia                  | <ul> <li>The Social: peer facilitated support group</li> </ul> |
|                         |                                   | for gay men 15 to 29 years of age                              |
|                         |                                   | <ul> <li>Women's Group: information and support</li> </ul>     |
|                         |                                   | group for women 15 to 29 years of age                          |
|                         |                                   | <ul> <li>+HELP: leadership and self-empowerment</li> </ul>     |
|                         |                                   | training   |
|                         |                                   | <ul> <li>Peer Facilitation Team: delivers peer-to-</li> </ul>  |
|                         |                                   | peer workshops in a variety of settings                        |
|                         |                                   | including schools and community                                |
|                         |                                   | organizations  |

## **Appendix C: Summer Camps for Youth Living with HIV**

| Canadian Camps               | Target Population and            | Services Provided                              |
|------------------------------|----------------------------------|--|
|                              | Program Description              |  |
| Camp Laurel Canada           | Children and youth living with   | - Educational, wilderness camp program         |
| http://www.teresagroup.ca/c  | and affected by HIV/AIDS, from   | - Opportunity for children and youth to        |
| amp.html                     | the Greater Toronto Area         | connect with their peers and build supports    |
| The Teresa Group             |                                  |  |
| 124 Merton Street, Ste 104   | Provide children and youth       |  |
| Toronto, ON M4S 2Z2          | with a happy, healthy,           |  |
| Tel: (416) 596-770           | rewarding experience in a        |  |
| Email: info@teresagroup.ca   | natural setting                  |  |
| Camp Moomba                  | Children living with or affected | - Provides camp and all transportation at no   |
| www.campmoomba.com/          | by HIV/AIDS, aged 6 to 17        | cost to families                               |
| Western Canadian Pediatric   |                                  | - Allows children the chance to just be kids,  |
| AIDS Society                 | Specialized recreational and     | supported by others who understand their       |
| 205-568 Seymour Street       | support program that builds a    | circumstances                                  |
| Vancouver, BC V5B 3J5        | fun, enriching, and supportive   |  |
| Tel: (604) 684-1701 or       | community                        |  |
| 1-888-442-KIDS (5437)        |                                  |  |
| Email:                       |                                  |  |
| info@campmoomba.com          |                                  |  |
| Camp Positive Families*      | Women living with HIV and        | - Includes regular camp activities, as well as |
| http://ccs-                  | their families                   | workshops on HIV medications and               |
| montreal.org/camp-positiv    |                                  | adherence, discussions about disclosure, and   |
| Camp Positive                | *Information could not be        | family yoga                                    |
| CCS Community Services       | located about this camp online.  |  |
| 1857, De Maisonneuve Blvd    | The information provided here    |  |
| Montreal, QC H3H 1J9         | was gathered from the            |  |
| Tel: (514) 937-5351          | Canadian AIDS Treatment          |  |
| Email: info@ccs-montreal.org | Information Exchange (CATIE).    |  |
| Camp Wendake                 | People living with HIV,          | - Traditional camp activities (swimming,       |
| http://campwendake.org       | including children, adults, and  | canoeing, campfire, arts and crafts, nature    |
| 190 Queen's Avenue           | couples                          | walks, and sports)                             |
| London, ON N6A 6H7           |                                  | - Massage, medication, and spiritual           |
| Email:                       | Provides an opportunity for fun  | exploration                                    |
| director@campwendake.org     | and fellowship with staff and    |  |
|                              | campers in a beautiful setting   |  |

#### A list of summer camps located in the United States can be found at

http://www.mysummercamps.com/camps/Special Needs Camps/HIV and AIDS/ or http://www.thebody.com/index/treat/camps.html.

## **Appendix D: American Programs and Services for Youth Living with HIV**

|  | Target Population and  | Services Provided  |
|--|--|--|
| American Programs  | Program Description  |  |
| Adolescent AIDS Program www.adolescentaids.org/heal thcare/about_aap.html Montefiore Medical Center 111 East 210 <sup>th</sup> Street Bronx, NY 10467 Tel: (718) 882-0023  | Youth living with HIV or at risk for HIV infection, aged 13 to 21  Strives to address the needs of the whole person and offers team-based services in a youth-friendly, confidential, and safe environment that empowers clients to make informed and responsible healthcare choices | <ul> <li>Comprehensive medical care and clinical HIV services</li> <li>HIV counselling and testing</li> <li>Individual and family counselling</li> <li>Youth support groups</li> <li>Youth Advisory Board</li> <li>Annual Youth Retreat and recreational outings</li> <li>Resource centre</li> <li>Research opportunities</li> <li>Coordinated care with other clinics (e.g., prenatal, psychiatry)</li> <li>Groups:         <ul> <li>Transitioning group in collaboration with the Montefiore Adult HIV Program</li> <li>Peer Education Program: trains youth aged 18 to 24 to become community outreach workers</li> </ul> </li> </ul> |
| Bay Area Young Positives (BAY Positives) www.baypositives.org 701 Oak Street San Francisco, CA 94117 Tel: (415) 487-1616   | Youth living with HIV, aged 26 and under  Peer-driven organization that supports the development and leadership of youth living with   | <ul> <li>Youth and family counselling</li> <li>Drop-in centre</li> <li>Referral services</li> <li>Social and recreational activities</li> <li>Support groups</li> <li>Weekend intensives</li> </ul>  |
| Boston HAPPENS (HIV Adolescent Provider and Peer Education Network for Services) www.childrenshospital.org/cl inicalservices/Site1849/main pageS1849P14.html Boston Children's Hospital 300 Longwood Avenue Boston, MA 02115 Tel: (617) 355-2735 | Youth living with or at risk of HIV, aged 12 to 24 years  Cares for youth and young adults in the Metropolitan Boston Area   | <ul> <li>Primary care and gynecological services</li> <li>HIV care and medications</li> <li>Full checkups and lab tests</li> <li>STI testing and treatment</li> <li>Birth control, family, and preconception planning</li> <li>Access to HIV clinical trials</li> <li>Case management and referral</li> <li>Individual and group therapy</li> </ul>  |

## **Appendix D continued**

| Family Ties Project www.familytiesproject.org The Consortium for Child Welfare 2120 Bladensburg Road NE, Suite 106 Washington, DC 20018 Tel: (202) 547-3349 | Families living with and affected by HIV/AIDS in Washington, DC  Provides permanency planning and life planning services, while advocating for policy changes   | <ul> <li>Child and youth case management, counselling, and advocacy</li> <li>Youth Development Program: provides enrichment activities, youth leadership programming, awareness and education services, and reproductive health services</li> </ul>  |
|---|---|--|
| The Laurel Foundation http://www.laurel- foundation.org/ 75 South Grand Avenue Pasadena, CA 91105 Tel: (626) 683-0800 Email: info@laurel- foundation.org    | Children, youth, and families affected by or living with HIV/AIDS  Empower children, youth, and families through educational and support programs in a safe and trusting environment  | <ul> <li>Residential wilderness programs (summer, winter, teen, and family camps)</li> <li>Day camp programs</li> <li>Counsellor-in-Training program (youth aged 15 to 17) to teach the skills needed to become volunteer counsellors at the camps</li> <li>Mentorship programs</li> <li>Life enhancement workshops</li> <li>Video support group: online, video support group for children and youth</li> <li>Collaborations with other AIDS organizations and support programs</li> </ul>   |
| Project Kindle www.projectkindle.org 28245 Ave Crocker, Suite 104 Santa Clara, CA 91355 Tel: (661) 257-1901 Email: info@projectkindle.org                   | Children, young adults, and families living with and affected by HIV/AIDS. <sup>3</sup> Improves the quality of life for clients through cost-free camping programs, year round support and advocacy, and peer-based HIV/AIDS education for young people aged 12-24 | <ul> <li>Summer camping programs (Camp Kindle) and mini-camping sessions</li> <li>Support, HIV/AIDS awareness/education, and mentorship</li> <li>Post high school scholarship fund</li> <li>"I Know" website: online resource for youth to learn about HIV/AIDS; social media aspect allows those living with HIV to educate others.</li> <li>Groups:         <ul> <li>SPEAK OUT (Sharing Personal Experiences and Knowledge – Our Unique Truths): peer-to-peer speaker's bureau</li> <li>Life Skills Retreat (ages 16 to 21): offers workshops and resources to help youth transition to adulthood</li> </ul> </li> </ul> |

<sup>&</sup>lt;sup>3</sup> In addition to their programs for those living with and affected by HIV/AIDS, Project Kindle offers programs for those with other serious illnesses, special needs, and other life challenges.

### **Appendix D continued**

#### University of California, San Diego (UCSD) Mother, Child, and Adolescent HIV Program

www.ucsdmcap.org 4076 3<sup>rd</sup> Avenue, Suite 301 San Diego, CA 92103 Tel: (619) 543-8089 Mothers, children, and youth living with HIV

Provides comprehensive, familycentred HIV care

- Multidisciplinary team provides medical care, clinical research trials, patient education, individual and family counselling, case management, peer advocacy, and community education
- Support groups for adolescents (aged 15 to 17), young adults (aged 18 to 24), and families
- Transitioning programs from pediatric to adolescent care (12 to 14 years of age), and from adolescent to adult care (up to 25 years of age)
- Groups:
  - Youth Program: provides health care and supportive services for youth up to age 25
  - Youth Council: youth and youth service providers who meet to discuss pertinent issues, advocate for other youth, connect youth to services, and plan educational programs
  - GLBTQQ Zone: provides services and support to GLBTQQ youth and their families
  - Children's Art Therapy Group: for children aged 11 to 14