

**Positive Youth and the Manitoba HIV Program Project  
Report Summary**

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**Background:** The Positive Youth and the Manitoba HIV Program Project was a pilot project undertaken by Nine Circles Community Health Centre and the Manitoba HIV Program, in partnership with the University of Manitoba, Faculty of Nursing and the Prairie Community-Based HIV Research Program (HIV CBR). This project was led by Dr. Roberta Woodgate (Faculty of Nursing, University of Manitoba) and Michael Payne (Executive Director of Nine Circles Community Health Centre). Other team members included Dr. M. Becker (MB HIV Program, Health Sciences Centre) and Paula Migliardi (Prairie HIV CBR). Funded by the AIDS Community Action Program (ACAP) resources, the project took place during the winter of 2010.

The aim of the project was to explore the perspectives of youth living with HIV, with an emphasis on Aboriginal youth, of the appropriateness of existing HIV services and programs offered in Winnipeg and to identify opportunities for improvement. A secondary aim was to assess youth's perspectives to involving youth in HIV-related research. The recruitment criteria were youth living with HIV/AIDS ranging in age from 18-24 years. When recruiting youth, diversity was sought with respect to gender, sexual orientation, and ethnicity. Youth were recruited via posters located at Nine Circles and at a Health Sciences Centre (HSC) outpatient clinic where youth receive care for HIV/AIDS. In total, ten youth ranging in age from 20 and 24 years, with 22 years being the mean age took part in the project. Eight youth were female (80%) and two (20%) were males. Six youth (60%) identified themselves as Canadian Aboriginal. The mean age of diagnosis was 19.5 years. Time since HIV diagnosis ranged from one to nine years with 2.7 years being the mean time. All youth were unemployed and the majority of youth identified themselves in the low-income bracket. For additional information please refer to Tables 1 and 2 (see Appendix A).

Each youth participating in the project took part in an individual open-ended interview that took approximately one hour to complete. The interviews were conducted between the period of February 1<sup>st</sup> and March 31<sup>st</sup> 2011. To facilitate discussion, an interview guide was used (see Appendix B). All interviews were digitally tape-recorded and later transcribed verbatim to preserve their authenticity. All but one youth were interviewed in a private room at Nine Circles. The other youth was interviewed in a private room at HSC. Data analysis was conducted by the first author and involved repeatedly reviewing the transcripts for significant statements in an attempt to find meaning and understanding through themes. Thematic statements were isolated by selecting and highlighting sentences or sentence clusters that stand out as thematic of the youth's experiences. Critical to this process was comparing and contrasting the data among each youth participant.

**Findings:** The findings are presented in three sections: 1) youth's experiences in utilizing existing HIV services; 2) key issues and challenges of youth utilizing existing HIV services and programs; 3) youth's recommendations to improving HIV services and programs; and 4) youth's perspectives to involving youth in HIV-related research. Unless otherwise indicated,

these findings were consistent for all youth participants. Direct quotes from the youth that help to exemplify some of the themes are included (see italicized text).

**Youth's Experiences in Utilizing Existing HIV Services and Programs:** The following three themes relate to youth's experiences in utilizing existing HIV services and programs emerged from the data: 1) I am not ready; 2) it is all about feeling comfortable; and 3) it is more than just HIV services.

*I am not ready:* *I am not ready* refers to youth's lack of desire and motivation to seek out HIV services and programs during the early years of living with HIV. The early years especially the diagnosis period were very stressful and frightening years for all youth participants. Regardless of time since diagnosis, all youth shared memories of how painful it was to be informed of their HIV diagnosis. This period was so intense that seeking out HIV services and programs other than direct care, was something clearly not on youth's minds. For example, instead of seeking out help one youth coped with the diagnosis by continuing to work on the streets and use cocaine. She reinforced that she was not ready to utilize any services.

*It was like the worst experience when I first found out but...How I dealt with it was I, I kept working and you know like getting high every single night. Just that's my way of coping with problems and that was a big one.* Aboriginal female

Youth expressed wanting to hide away from everyone and to be in their own space as reinforced by the following comments,

*I don't remember how far along I was like four months or something like that. I think and then I don't know. Gotten the call and then I went and thought that maybe it was going to be something else and then it was that (the HIV diagnosis). And after that I couldn't stand being in public for awhile just looking at other people. Oh yeah at first it was and then I guess I just had to get over it.* Aboriginal female

*Um, well first of all I would probably tell them like just because most people when they first find out right they're all like in a shell, right! And um that's how I was, I was always in a shell like always don't want people around me because I would like always cry. You know, it is very hard news to take.* Aboriginal female

How long it took for youth to be ready to seek out services and programs varied with youth. For some it took a couple of months and for others, years. Having the support of a friend, family member, or health or social service professional helped youth to deal with their fears associated with seeking out services and programs. However, even with the support, youth were not always ready to move forward.

*And I told you know like, actually I just found out a friend of mine was diagnosed and um you know she was freaked out, like she didn't know what, because she's younger than me. You know and she was like really scared and you know I actually told her, I was like yeah you know what you should go to Nine Circles and you know they'll help you like they'll explain everything to you. And she's like, 'well I'm afraid to go there*

*by myself' and you know I offered to take her but I don't know, whenever she's ready right to take that extra step.* Aboriginal female

In addition to the diagnosis, other conditions (e.g., abuse, relationship problems, pregnancy, addiction problems) in the youth's lives influenced their readiness to seek out services and programs. In having to deal with the many challenges in their lives, youth reinforced that they just had too much on their plate to have the time to seek out services and programs.

*No programs now! I don't know, I haven't gone to any. I didn't think that I would have to go. There's a lot going at the time. Having my baby...just me hoping my baby was going to be okay and just everything that went on. Usually when I go see them (clinic) I don't really pay attention. Kind of all over the place, huh...* Aboriginal female

*Hmm, well at the moment actually I kind of have a lot on my plate right now. I'm just not thinking about so much of um other programs at the moment.* Aboriginal female

**It is all about feeling comfortable:** Throughout the interviews youth consistently reinforced the importance of feeling comfortable with respect to accessing HIV organizations, services and programs. Youth talked about how important it was to have a 'good feeling' about the HIV organization that they attended. Youth reinforced that if they did not 'get that feeling' about the organization that they would not attend it even if it provided the appropriate services for them.

Feeling comfortable was the result of a number of elements. First and foremost, were the people providing the service or program and how they responded to youth. The fear of being judged was especially prevalent during the diagnosis period. Youth expressed that entering an HIV organization could be more hurtful than helpful to them and hence, this contributed to their fear of seeking out services or programs. Individuals who made youth feel uncomfortable resulted in youth having limited contact with the organization. Youth reinforced it was important for service providers to be nonjudgmental.

*Um well yeah it is helpful cause like they're (HSC) like cool about it like they're not like judgmental, at least I don't think.* Aboriginal female

*Um well I'm sure, well I was like nervous and didn't really want to come, it's like just the fact of getting through it, getting like more comfortable about it. So it's like if someone judges you, if someone judges you it's like not the end of the world I guess. But it is like hurtful and it's like...It's not very good to deal with and it puts a lot of stress on you and I don't know.* Aboriginal female

Youth needed to be able to trust those individuals responsible for providing services and programs. Contributing to a sense of trust were relationships that involved treating youth with respect. Service providers who exhibited the characteristics of honesty, sensitivity, and compassion were integral to the development of trusting relationships.

Youth reinforced that they wanted service providers to 'treat them just like any other person.' They also appreciated service providers who showed that they cared and who truly were able to help them.

*Yeah, there was a bunch of them that were kind of involved. I can't remember all their names. I know there was a pharmacist. He was really nice. "A" she's really nice. She helped me get what I needed for like my health problem and my, my workers helped me so. And I can't remember the other ones and I know there's one doctor Dr. "C" that helped and talked to me and stuff... Aboriginal female*

*So I have a good doctor, I have a good nurse. In that FAS program they're really good to me, they bring me to my appointments here and take me home and grab me a meal and stuff like that. Aboriginal male*

*But when they talk to you more about it and know more or less about what you're not knowing and knowing about, then it's like really helpful. So sort of like listening to the doctors when they tell me things, so like I can go back on it and do the right thing. They were helpful, like they always used to, like tell me like how I should take my meds all the time, make sure not to do this and not to do that. Aboriginal female*

Youth reinforced the importance of seeing a friendly face upon entering any organization or clinic providing HIV services or program. The first person they encountered needed to be warm and welcoming. One youth spoke of the friendly receptionist at one of the HIV organizations and how easy it was to talk to her.

In addition to those individuals who youth perceived to be judgmental, youth also felt uncomfortable by individuals who youth perceived were harassing them. Some of the youth shared experiences of feeling harassed during their initial encounters with service providers responsible for obtaining information about their status and partners. Youth also did not appreciate 'being lectured to' when attending appointments or during counseling sessions.

Youth really appreciated service providers who youth felt comfortable enough to talk to them about how they felt living with HIV.

*Actually I think it's just talking, talking, a lot of talking about it, things that are more comfortable to talk about the situation. So if there's someone there to just always talk to you and like that you're comfortable talking to all the time, then it makes it more easier and more and more like talk about, I don't know it makes me feel comfortable cause like I've talked to um doctors at the hospital for quite awhile now. Aboriginal female*

A couple of youth were uncomfortable attending an organization or program because of the other clientele who attended the organization or program. For example, some youth were not comfortable around individuals who were drug or solvent users.

*Um there were some solvent users that had frequented the place so I know that made people feel very uncomfortable...I think it was a lot to do with the glue sniffing,*

*the solvent to be honest you know glue sniffing. The thing I don't like is that, the solvent you smell in here. Yeah. That's something I don't like.* Aboriginal male

Some youth noted that they have to adjust to being around other youth with HIV.

*Because I had to get used to like being around other people when they're sick and you know like because there's one girl there I know. And we like we didn't hit it off in the past you know. Um because like my boyfriend ripped her off and you know. And um and it was like kind of freaky, like just knowing that she knows I'm sick now and you know there's certain people I don't want to know...But now I just love being there (House of Hessed). Uh, it was just like the, like I get along with like the people that live in there. And you know we have our laughs like yesterday was like the best night ever. Yeah because there's this one girl named "M" she works there and you know it was like; she's like one of the best staff members. She acts like, like our age you know. Like she's a kid at heart you know.* Aboriginal female

Overall, youth expressed that it takes time to feel comfortable to talking to others about their HIV diagnosis.

*Yeah, it just took like, well some time for like people to get comfortable with everything, so then I got more comfortable about it too in talking about it. But still like when a situation is brought up I still feel uncomfortable or like if someone like, if someone's having a talk, a group session and like they don't know about my situation then I get uncomfortable like does someone else know about like me or you know, something like that.* Aboriginal female

***It is more than just HIV services:*** Youth reinforced that services and programs offered to youth need to be '*more than just HIV services.*' In addition to what youth referred to as HIV services (i.e. health care services), youth felt the following services or programs were important to improving youth's well-being: counselling (includes individual and group), social welfare services, food banks, use of computers/phones, journaling programs, educational programs, Living Well with HIV program, and Aboriginal programs. Youth listed a number of organizations that helped them to access the various services and programs: Klinik, Health Sciences Centre, Mount Carmel, Nine Circles Community Health Centre, House of Hessed, New Directions, and Street Connections.

*And that's about it and Nine Circles will help you with housing here which I got into housing right away through Nine Circles, Manitoba Housing, but I waited for a year and seven months to get into that.* Aboriginal male

*I just come to see a doctor and use the Food Bank or the phone or the computers. Or to uh look what's coming up like what kind of outings they're having. It also was like a second home to some youth. It was going to the place to hang-out.* Aboriginal male

Organized social activities or outings were also identified as important activities for youth. All of the Aboriginal youth who participated in the project talked about the types of cultural or spiritual programs that they found helpful.

*Like the last outing I went to was a Two Spirit gathering in Beausejour that was last spring or summer. So I was out there for a week. It was a, was a native gathering with two spirited like gay lesbian and all that. It was good.* Aboriginal male

**Key Issues and Challenges of Youth Utilizing Existing HIV Services and Programs:** The following three themes relate to the key issues and challenges utilizing existing HIV services and programs: 1) not knowing all that is out there; 2) painful feelings; and 3) roadblocks in the system.

**Not knowing all that is out there:** While each youth was able to list a number of HIV organizations, they were not fully informed of all organizations that could be potentially beneficial to them.

*Well just like Nine Circles and then um like some counsellors and stuff that were here and my doctor. I only really kind of know about Nine Circles. Like I know there are other places. I don't remember the names of them but...* Aboriginal female

'I never knew there was a place like' was often a common response made by youth when being introduced to a new organization. Youth were also not always aware of what was all offered by the organization(s) that they attended.

*Yeah, when you have an appointment like in the afternoon but you see your worker during in the mornings and you need to get a ride there. But I didn't even know you can phone welfare and they can give you a taxi slip. I didn't even know about that.* Aboriginal male

In finding out about potential services and programs, most youth were informed directly by a service provider. Friends were also a source of information. Youth found posters or information sheets on bulletin boards at HIV organizations to be a helpful source of information. A couple of youth also talked about accessing books and the internet for their information.

For some youth the 'not knowing' was by choice in that they had no desire to find out about any new and/or additional services and programs that could potentially benefit them.

**Painful feelings:** Youth shared numerous instances about how their feelings influenced their ability and desire to seek out services or programs. Again, this was especially the case during the diagnosis period and the first year after diagnosis.

*And, and I found that I had HIV that really set me back on a lot of things. Cause I was very young (17 years) at the, at the time when I had found out. So now that I'm more like, um the years went on and kind of getting more comfortable talking about it. And not so much like uh, like before when I first found it, like it was really hurting me. Like*

*I didn't really talk about it that much but now that um its more out in the open with everyone else I'm more comfortable, I guess. Aboriginal female*

Youth experienced negative feelings towards themselves such as shame and disgust after receiving the diagnosis.

*I just felt like gross and dirty after the diagnosis. Yeah till this day it still makes me feel like uncomfortable. Yeah. And yet I'm still very young and I had this for like almost three years now. Aboriginal female*

The shame experienced was so intense for some that they expressed not wanting to be seen by anybody for fear of being ridiculed.

*Because I just found out right, so I was like really embarrassed like going into, like, like the HIV part of it right. I was really scared to walk in there (HSC). Cause I was like worried about being judged or...because there's a lot of people that judge people with this sickness right. So that's how I felt and I just put my head down cause I was ashamed of myself and...Aboriginal female*

Youth reinforced that it often was the persistence of a friend, family member or service provider that they get help that made them seek out services. However, when they did seek out services some youth expressed being made to feel even more shame by how the professional responded to them.

Fear was another feeling that made it difficult to for youth to seek out services. Again this feeling was more common during the diagnosis period and was associated with how having HIV could result in an early death. Also contributing to youth's fear was the concern that others could find out that they have HIV. Youth expressed fear that others would see them enter a HIV organization. .

*I was shy to go there (Nine Circles). Cause you know people walk by you and they'll recognize you, what you're doing there. So I just tried my best to hide. Aboriginal male*

*Hmm well like knowing like people like knowing that Nine Circles is an HIV/AIDS like place, to me it's kind of like embarrassing to like know that people see you coming here and hanging around and like does she have it or does he have it, you know like kind of thing. People just judge by coming here. Aboriginal female*

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Youth also experienced fear in disclosing their HIV status to friends and families. The fear experienced by some youth meant that they did not receive the much needed support from those around them.

*Already and then I'd gotten a call and I was just kind of scared like why they had said 'oh you need to come see us.' It's important and I went and then I found out. At first I was scared and really sad and didn't tell anybody. Yeah. And then so yeah I was basically scared to tell them, anyone. At first I didn't tell anybody. Well at first nobody really said anything at first when I found out I told my sister. I didn't tell her exactly, yeah but she's crying then I told her and (short pause) yeah. Aboriginal female*

Overall the painful feelings experienced by youth sometimes resulted in actions that put them in harm.

*I was so sad and scared I just thought I had to just and I felt stupid because I was pregnant and I went and drank cause I didn't know how I was to deal with it and I wanted to hurt myself. Aboriginal female*

**Roadblocks in the system:** This theme referred to the youth's perspectives of the barriers in the system that made it more difficult for youth to access services and programs. The barriers included:

- Location of HIV services and programs: The distance factor was something that youth found to be a problem when accessing services and programs. Some youth found services and programs to be located too far away or not close enough to where they lived.
- Problem with how appointments are scheduled: Some youth felt that appointments were not scheduled in a manner that fit with their own lifestyle.
- Waiting for services and programs: Some youth experienced having to wait too long before getting into a particular service or program.
- Funding problems: Some of the youth expressed that getting adequate funds for existing and/or future services and programs is a problem. Youth expressed concern that funding problems lead to inconsistencies with respect to how services and programs are offered, and even result in a loss of services and programs. One youth noted services that start out really strong or promising, eventually run out of funding and thereby result in changes to the clientele they serve. When asked to identify what additional services and programs are needed for youth, another youth commented '*but where are they going to get that funding from. It is a problem!*' Aboriginal male

**Youth's Recommendations to Improving HIV Services and Programs:** Youth provided a number of recommendations that they felt would help to improve HIV services and programs for youth in Manitoba. The recommendations as represented by the following themes are: 1) more awareness; 2) more of everything; 3) more youth-specific services and programs; and 4) more school involvement.

**More awareness:** Of all recommendations, the need for more awareness about HIV was the recommendation most talked about by youth. Overall, youth reinforced the need for more



awareness about HIV/AIDS and getting the message out there about HIV/AIDS. This included education directed at youth (with and without HIV/AIDS) that focused on all aspects of sexual health including HIV/STD risk reduction. Youth could not emphasize enough the importance of educating youth. Youth felt that sexual health education needed to be more detailed especially with respect to providing information about having safe sex. Youth were really concerned about educating others of the dangers of unprotected sex.

*Oh probably a school to teach kids about HIV and all that. Like stuff like AIDS and all that that would be something like just a small little group at school who are interested in there and take that information back to our family and tell them that you guys better watch that. Instead of just going all crazy and having sex. Aboriginal female*

*Yeah like they can um put something more into that, talk more about. Talk more about like HIV and AIDS and everything else. And the clinics in schools and letting kids know more and more about that it is out there and that the rates are like growing and to be more careful. To talk about it if they want help and resources, like there are help and resources out there. And then, in like yeah schools I think is the first place to put it to let them know to be careful and be like very like mindful of like really scary things like this like viruses and other transmitted diseases. Yeah and letting kids know that like yeah, I guess health classes and clinics. Aboriginal female*

Youth felt that more sexual health education including safe sex was especially needed in schools. In addition to providing more education in schools, youth felt there was need for more 'information centres' and 'drop in education programs' offering sexual health education that was meant for 'everybody.' Youth felt that information about preventing STDs should be available beyond centres that deal with STDs. Youth also felt that the emphasis of the education should not be placed on 'numbers' but on 'people' with respect to how STDs impact the lives of individuals living with STDs.

Youth emphasized that in addition to sex education, youth with HIV needed more education about what will help them deal with living with HIV. This included information about the social and legal aspects related to being diagnosed with HIV. Youth with HIV in general just wanted more information.

*Yeah um it's just I think they, like the people they need to know, like they need to know more about this disease. Yeah because they, yeah they give you like the little like tips here and there right. But I think the doctors should give more advice about it or give more definition like on the sickness. Cause I am, I'm still learning about it and it's been like a year and a half. You know, and because I'm not being told exactly what it does or...Um but yeah I've been reading that up on my own, seeing what it really does to your body because I really didn't get that explanation right. Aboriginal female*

In addition to youth receiving more education, the youth in this project reinforced that the public needed to be educated with respect to what it is like to be a youth living with HIV and how it feels to be treated differently because of their HIV status. Youth wanted others to

know that youth with HIV are not 'lepers.' It was important to teach others how they should really treat youth living with HIV.

Youth offered a number of avenues that could be used to get the message out there including MuchMusic, the internet, posters, pamphlets, and cartoons. Youth also felt that developing awareness booklets that could be distributed to schools and HIV organizations could be helpful, as well as other public places like libraries and churches.

**More of everything:** In general, youth felt there was a need for more of everything with respect to the provision of services and programs for youth living with HIV. Youth expressed the need for more HIV organizations and services to be located throughout the city. Regardless where they lived, youth want the services to be easily accessible for all youth.

*Well I think that there should be more programs in like every area of the city because I know like some areas don't offer stuff like that um and I know there is like that those trucks that drive around downtown. But I think they should like be more spread out like. Aboriginal female*

Youth also wanted services and programs to be accessible '24/7' throughout anytime during the day and night. 'Drop-in centres' where youth could come and go and hangout anytime were also recommended.

*Accessible and I mean you've got Nine Circles but you're not really allowed to like hang out for any specific amount of time. They have some programs here throughout the week that you know try to cater to people and uh you know they have some good turnouts and its great but it's not quite, you know there's... Aboriginal male*

Youth also expressed the need for more people working in HIV organizations. They wanted more people in terms of number but also in terms of quality. Youth expressed there was need for more people working in HIV organizations who were caring, warm, and sensitive to youth living with HIV.

**More youth-specific services and programs:** Youth felt that more services and programs need to be geared to youth. Youth felt this was necessary considering there are more youth with HIV.

*Cause there's more, well what I'm finding out that there's more like, more people that are in my age group getting diagnosed like lots, like the rates are picking up like, like what I hear from doctors like lots, so if someone can make like something happen for that age group and make our teens and everything feel more comfortable about that. And talk about it and you know, knowing is knowing but that's just something but that would be a good thing to hear more about. Something like where somebody can go comfortably or group time or something anyways with that age group, that would be good, I would probably go to it. Aboriginal female*

Youth felt youth-specific programs are needed because youth are more vulnerable compared to adults.

*Right because most young people are scared, right! Um and like the older people they don't really, well they care but they don't really care like if they have it or not. But the young people they're embarrassed because their friends would know and you know, so they do need more people around this age range to participate in some, something like. There's like not very many programs, it's for all ages pretty much.*  
Aboriginal female

Youth emphasized that in developing youth-specific services and programs it was important to consider how youth would feel about utilizing such programs and services.

*Hmm probably just more of like the resources like. And like how like they feel going to those resources, just to make them feel comfortable or if they're not comfortable or not too sure about going to them.* Aboriginal female

Youth stressed that services and programs geared for youth needed to be interesting for youth.

*Stuff that is interesting! Stuff that will keep their mind off it. Just yeah stuff like that. Stuff I'd be interested in well I don't know like camping, camping's fun. Yeah, getting out of the city, getting away from everything.* Aboriginal female

*There's booklets about that but that's for like adults but the younger ones. Unless they can sound like funny or something.* Aboriginal male

Except for social and cultural activities and outings and workshops on how to live independently, youth did not provide ideas about the types of services and program needed for youth. However, youth did stress that youth need to have a voice in the development of services and programs for youth and HIV organizations need to involve youth. Youth expressed that youth should become part of the programs themselves as board members, committee members, or as program advisors.

It is important to note that although youth wanted more youth-specific services and programs that youth felt there were times it is beneficial for youth to interact with adults living with HIV. Youth felt this would help reinforce to them that it is possible for youth with HIV to grow into adulthood. As well, youth felt adults with HIV have experiential knowledgeable about what it is like to live with HIV that they could share with youth. One youth suggested having a 'buddy system' similar to the Big Brothers/Big Sisters organization where youth could be partnered with adults experienced with living with HIV.

**More school involvement:** Youth felt that more HIV services and programs needed to be provided or offered through the schools. In addition to educational and counselling programs, youth felt school should have clinics that could address all of youth's sexual health needs. Accessibility and privacy are features that youth felt schools had to offer.

*But one girl was saying that at her school they have like a clinic there every Tuesday. And that would be like a good idea to do that at a lot of schools. Cause I know like a*

*lot of like kids wouldn't be comfortable you know telling their parents about it and stuff. Well it was for like STD testing or STI or whatever like. And pregnancy tests, stuff like that. Yeah, which is kind of neat like to have in a high school. Cause you don't hear about that too much. Aboriginal female*

Youth reinforced that there needs to be 'more talk' in schools about HIV/AIDS.

*Talk more about like HIV and AIDS and everything else. And the clinics in schools and letting kids know more and more about that it is out there and that the rates are like growing and to be more careful. To talk about it if they want help and resources, like there are help and resources out there. Aboriginal female*

**Youth's Perspectives to Involving Youth in HIV-Related Research:** Overall, youth stressed that it was important to ask youth their opinions about their experiences with living with HIV as well as their experiences in accessing HIV services and programs. Youth indicated that this dialogue should be ongoing.

*You know that's it. Uh you know it, it's just asking questions, its people who asking the right questions, collaborating to come up with an idea and yeah you have to get the people on the frontlines that are dealing with the youth to start asking the questions and wanting to do something about it... and uh just listening to the youth cause that way too you're going to get what the youth want. Aboriginal male*

However, while it was important to ask youth their opinions about HIV services and programs, youth reinforced that their opinions needed to be acted on in a timely manner. Youth stressed there is no point doing research if the findings are not used to make improvements in HIV services and programs for youth.

Youth also recognized that it was important for youth to get involved and to give back, and that this could be accomplished through their involvement in research or other avenues.

*And you know I think it's, it's pretty much straight across the board, it don't matter where, where you, who you are or what your health is, you know just staying involved in whatever it is, whether its cancer or, or you know a cause you know children's rights or...you know just uh start getting involved on the ground level and there's ways of volunteering your time then and you know sometimes it has some benefits and other times it doesn't but uh like you know it just it helps to make a change. Aboriginal male*

However, youth noted that it was important to recognize that some youth may be at a stage in their life in which they are not yet ready to get involved.

Youth suggested that inviting youth to become involved in research or services or programs could be mainly done through advertising such as putting up posters in clinics or via pamphlets or newsletters. Another good way to reach youth is through word of mouth.

## **Main Points and Conclusions**

- The diagnosis period and the period following the diagnosis is a very challenging and stressful time for youth that impacts how they access HIV services and programs. While this project provided some understanding of the early years, further study is warranted in order to ensure that services and programs fit with the needs of youth who are newly diagnosed.
- Providing services and programs in an environment that promotes a feeling of comfort in youth is critical to ensuring that youth will access HIV services and programs.
- Youth with HIV experience many painful feelings especially during the early years that impacts how youth access HIV services and programs. More needs to be done to help youth deal with their feelings so that they will feel comfortable accessing services and programs.
- Youth value services and programs that are diverse and deal with the whole person and mind and body. Services and programs should be focused on promoting a positive sense of well-being in youth with HIV.
- Although youth were able to list a number of services and programs meant for youth with HIV, they nonetheless lacked information of all possible services and programs. More needs to be done to advance youth's awareness of HIV services and programs.
- From youth's perspectives there are barriers in the system that need attending to that will make it easier for youth to access services and programs. A more detailed investigation of system problems is needed.
- A three-pronged approach to an awareness and education campaign is called for that is focused on promoting an understanding in: 1) youth about all aspects of sexual health including HIV/STD risk reduction; 2) youth living with HIV about what will help them deal with living with HIV; and 3) the general public about what it is like to be a youth living with HIV.
- Youth support the need for more youth-specific HIV services, programs, and research.
- School-based HIV services and programs from the perspectives of youth have the advantages of being more accessible and private.

**Limitations:** There are two major limitations. First, the sample was small and limited with respect to diversity in age range and gender. Further work that includes involving more Aboriginal youth representing a wider age range and diversity in gender is needed. Secondly, understanding how the perspectives of youth change over time was not possible as this was not a longitudinal project. However, the strength of this project is that it provided grounding for future study.

**Future Directions:** In the short term, the information gained from the youth will be used within Nine Circles and the Manitoba HIV Program for 2011/12 program planning and shared with project partners and identified youth serving agencies as a program planning resource.

**Future Research Plans:** Additionally, this project provides grounding for a study that the investigators plan to submit to the Canadian Institute of Health Research (CIHR) Community Based Research HIV/AIDS operating grant program (October 2011).

Considering the diagnosis period and associated feelings had such a major influence on youth's experiences in accessing HIV services and programs, we plan to undertake a study that is focused on the early years of youth living with HIV. Questions to be asked include the following:

- What are the needs of youth who are newly diagnosed with HIV?
- What services and programs are needed that will help to meet the needs of youth who are newly diagnosed with HIV?
- What helps to get youth who are newly diagnosed with HIV to that place in which they are ready to accept services and programs?
- What helps youth to accept their HIV diagnosis?
- How do youth with HIV transition from the diagnosis period to the first year of living with HIV?
- What services and programs are needed that will help youth with HIV to transition from the diagnosis period to the first year of living with HIV?

**APPENDIX A****Table 1. Demographic Information for Nine Circles Participants**

<b>Characteristic</b>	<b>N</b>	<b>%</b>
<b>Age (N=10)</b>		
18	0	0
19	0	0
20	3	30.0
21	0	0
22	2	20.0
23	2	20.0
24	3	30.0
<b>Gender (N=10)</b>		
Male	2	20.0
Female	8	80.0
<b>Currently in school (N=10)</b>		
Yes	3	30.0
No	7	70.0
<b>Highest level of Education (N=10)</b>		
Grade 7 or below	2	22.0
Grade 8-10	0	0
Grade 11	6	60.0
Grade 12	2	20.0
<b>Employment (N=10)</b>		
Yes	0	0
No	10	100.0
<b>Dwelling type (N=10)</b>		
House	5	50.0
Apartment	5	50.0
<b>Ethnicity (N=10)</b>		
White	4	40.0
Aboriginal	6	60.0
<b>Lifelong citizen of Canada (N=10)</b>		
Yes	10	100.0
No	0	0
<b>Income (N=10)</b>		
Low	9	90.0
Middle	0	0
High	1	10.0

**Table 2. Age at Diagnosis**

<b>Code</b>	<b>Current Age</b>	<b>Time since diagnosis</b>	<b>Age at Diagnosis</b>
1	24	6 yrs	18
2	24	9 yrs	15
4	24	1 yr	23
5	20	1 yr	19
6	23	1 yr	22
7	22	1 yr	21
8	23	1 yr	22
9	20	3 yrs	17
10	22	1 yr	21
11	20	3 yrs	17

## APPENDIX B: INDIVIDUAL OPEN-ENDED INTERVIEW GUIDE

**Notes:** Questions and Probes will only be asked as necessary. The probes (marked with an o) are meant to stimulate discussion. Participants will be reminded that the interview is voluntary and they can choose not to answer any questions that they would prefer not to answer

1. Can you please tell me a little bit about yourself/your HIV/AIDS diagnosis?
2. What type of needs do you have?
  - o What are some of the things that you need that help you in your everyday life?
  - o Who/What helps you to meet your needs?
  - o How have your needs changed since your diagnosis?
3. Can you please tell me about the types of services and/or programs that you use? (Please have the youth talk about each service/program individually.)
  - o Can you please tell me about your experiences with accessing these services/programs?
  - o Can you please tell me about your experiences with using these services/programs?
  - o What do you like about these services/programs?
  - o What do dislike about the services/programs?
4. What services and/or programs do you feel help you the most to deal with and manage living with HIV/AIDS? Please explain.
  - o What community services and/or programs would you recommend to other young people living with HIV/AIDS?
  - o What community and/or programs would you be least likely to recommend to other young people living with HIV/AIDS?
  - o What service/programs have been most helpful?
  - o What service/programs have been least helpful?
5. What suggestions do you have on how to improve existing services and programs?
  - o How would you like to see existing services or programs change or improve?
6. Overall, are there any services or programs that you feel are needed but are not available?
  - o What suggestions do you have on the type of service/programs that should be developed?
7. How can we help those youth living with HIV/AIDS who would benefit from HIV/AIDS related services and programs, but who do not make use of existing services and programs?



8. What advice would you give to professionals and others working with youth living with HIV/AIDS about how they can best support HIV services and programs meant for youth?
- What advice would you give to professionals and others working with youth living with HIV/AIDS about how they can best help youth in their use of HIV services and programs?

**Today we would also like to know if/how much this study and other studies that focuses on the experiences and perspectives of youth living with HIV/AIDS is relevant to youth like you and others.**

9. Can you please tell me what made you decide to take part in this study?
10. What other questions could we ask youth participating in this study that you think would be helpful to this study? Please describe.
11. In addition to focusing on youth's experiences in utilizing HIV services and programs, what other areas do you feel are important to study that would help to improve the lives of youth living with HIV/AIDS?
- Do you think these areas are different for positive and non-positive youth?
  - If we were to do another study like this, what questions would you like to see being asked? What areas of study should be focused on?
12. In what ways do you think youth should get involved in HIV related research?
13. Is there anything else you would like to share with us about your thoughts with regards to involving youth in HIV related research?

#### **Ending Question**

14. Is there anything else you would like to talk about that we did not talk about?

