



The Truth *about* Youth

With HIV infection rates among young people on the rise it's clear that we've all got to do a better job of reaching out. But how? We asked the experts—positive youth—what needs to change.

BY COLLEEN PATTERSON

Young people under 25 make up half of all new HIV infections but are often excluded or ignored as key players in the fight against HIV and AIDS.

—Toronto YouthForce Advocacy Task Force
Final Narrative Report, September 2006

Among the loudest messages delivered at the XVI International AIDS Conference held in Toronto last August was this stark reality. And with no sign that this trend will improve, the need for leadership by and for young people with HIV is more urgent than ever. The barriers, unfortunately, are considerable.

Lynn Thompson is an Aboriginal woman in Winnipeg, Manitoba, who has been living with HIV for five years. An AIDS advocate for women, Thompson also does outreach with positive youth—at least she tries to. “Here, the youth are just plain afraid of coming out,” she says. “I’ve actually never met a youth here who is willing to come out.”

There are many reasons that prevent young people with HIV from feeling safe enough to seek support. Among them, stigma, discrimination and fear. Accessing services can also be very difficult for a youth. In fact, Thompson says, “As

advocates and service providers, we have to find the youth because often they are not coming in until they are really sick and very bitter.”

A Matter of Survival

For many marginalized positive youth, life is simply about surviving. The harsh reality is that many are struggling with issues such as addiction, abuse (sexual, physical, emotional) and lack of housing or a safe place to live, wondering where and how they are going to get their next meal. They have little room to be concerned with things like adherence, nutrition and changing behaviours.

Thompson knows the challenges too well: “There is housing for people who are on disability and when you disclose your health status you’re told it won’t affect your application. But I’ve been homeless for four months in Winnipeg. And I’m 39. I can’t imagine how a 20 year old would even find housing if he or she has to disclose health status. If this were happening to me when I was 20 years old, I certainly wouldn’t have wanted to come out.”

Kecia Larkin, an Aboriginal woman living with HIV in Victoria, British Columbia, is concerned because the city offers no support for her family members, who are affected by her status. “I can’t take my kids to any AIDS service organization because there is no support for them,” she



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- Offers a wide range of material geared to youth, including: The Basics, Positive Life, a Library, Message Board, Art Gallery, Fun Stuff (interactive games), Positive Heroes and a Poetry Corner.
- Developed through a partnership between Positive Youth Outreach (PYO), The Hospital for Sick Children Divisions of Adolescent Medicine & Infectious Disease in Toronto, CATIE and TeenNet at the University of Toronto in collaboration with youth and youth-serving agencies across Canada.

says. “My daughter is 14 and there is no place for her to go for support, no place for her to go to have a community.”

HIV-positive youth have to deal with many complex issues concerning the disease that are unique to people of their age group. Among the most challenging is finding programs and support systems geared to their needs and attitudes. Until society and, in particular, AIDS support systems realize this and act accordingly, there is little anyone can do to make a real difference.

That Big First Step

Danielle Layman-Pleet, 30, former executive director of Voices of Positive Women in Toronto and HIV-positive for six years, sees the need for more and better youth-specific services. “If and when a young person steps through the doors of an AIDS service organization (ASO), it is a really big step,” she says. “If they’re not made to feel they are being served and supported, they’re not going to come back. And that is often what happens, especially with marginalized youth. If you’re pushed away, chances are it’s going to take a long time before you come back...or you don’t come back at all” (see “The Keys to Serving Youth,” page 15).

All too often this is the case for youth. They come in seeking help and advice, and they want it from someone their age, who shares similar experiences, with whom they can connect

and learn from. Youth who are positive have had less opportunity to experience life than their adult counterparts and are still figuring out who they are and what they want to do when they grow up. Often they haven’t had the chance to establish themselves in their jobs or career of choice. Some may not have finished school. In addition, youth more than adults are much more likely to be defined by their HIV status.

Still, while most everyone would agree that there is a pressing need for more programs created *by* young people with HIV *for* young people with HIV—with on-site mentors to help guide them through the bewildering experience of being positive and young—the remedy is not at all straightforward. Lia DePauw, 32, a specialist in youth development and health promotion in Toronto, knows this from experience. “Organizations and services run by both adults and young people often recruit youth staff and volunteers who come from privileged backgrounds,” she says, “perhaps because resources are stretched and they want youth who have ‘skills.’” These “privileged” youth usually tend to be university-educated and very interested in HIV but they may not be personally affected. Angel Parks, 30, agrees it’s a problem. “You want to feel you are dealing with someone like you, who understands you.” Diagnosed four years ago, Angel is both a client and a volunteer at Positive Youth Outreach in Toronto. “ASOs need to observe GIPA [greater involvement of PHAs],” she says, “to create a place of diversity and acceptance.”

The Future is Now

Layman-Pleet sees another issue: “It is vital in the HIV movement not only that there are youth in leadership roles but that they are mentored, because they are the future of the movement.” When a young person is brought into a youth organization or ASO (whether they are HIV-positive or negative), there needs to be a support structure in place specific to his or her needs. “It is important when you put youth in various positions within an organization that you prepare them for that role,” says Marco Gomes, a 27-year-old Torontonians who was diagnosed with HIV in 2004 and is a strong advocate for HIV-positive youth. “For example, if you are going to put a youth on a board, that youth has to have a mentor. All boards have specific mandates; a youth may have a lot of ideas but perhaps they are not within the mandate of that board. Having a mentor to help the youth understand and gain tools will make their work much more effective.”

Sonika Lal, 28, who has worked in HIV/AIDS and in sexual and reproductive health and rights, agrees. “Being a young person in the field, your ideas and thoughts may be considered fresh and innovative or they may not be considered at all,” she adds. “I think there is sometimes the mentality that young adults are ‘tomorrow’s leaders’ rather than already being leaders who can engage and participate in decision-making roles. The unique life experiences of young people are vital resources.” She also

acknowledges that young people have a lot to learn from their adult colleagues. “I was lucky enough to have great mentors who I not only learned from but who challenged me and gave me great advice.”

Having mentors and structures sensitive to the particular vulnerabilities of youth not only increases the likelihood of success for any young person accessing services or working within an organization, it can also protect them from, for instance, inappropriate sexual comments and advances (a surprisingly common complaint from many in this situation). It is all too easy for the power relationship that can exist between adults and vulnerable young people to result in resentment, alienation and even deliberate exploitation. When an older person abuses a position of power and privilege, a youth will be left feeling uncomfortable, violated or even more isolated than before he or she sought support. Often this type of inappropriate behaviour starts out subtle and escalates into more obvious and overt forms of harassment. Often youth do not realize they are being treated inappropriately until it has gone too far. Organizations serving youth need to ensure that essential safeguards, policies and structures are in place so that effective support and mentorship can take place.

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Token Gestures

There are other challenges. Alex McClelland, 28, who may be the most prominent positive youth activist in the country, has run into his own set of hurdles. “[When I tested positive] all I wanted was someone my age, a peer with the same experiences to share, to help me understand how to live through the trauma of the whole experience,” he says. “Instead, I spent a lot of time feeling uncomfortable and out of place. I had quite a few bad experiences.”

In retrospect, McClelland realizes that he was asked to take on more than he was ready for at the time. “All I wanted was support, but instead I was thrust into a leadership role,” he says. “I was often asked to take part in workshops and presentations as a speaker. I think I was way too young and vulnerable to be doing it. I was exploited so social workers and others could learn ‘how to work with youth.’”

The problem is that the very organizations that are trying to help often unwittingly compound the problem. “Organizations often resort to tokenism without realizing they are doing it,” says Layman-Pleet. “This happens when structures are not set up to equip the young person with the tools they need.” McClelland,



diagnosed with HIV almost 10 years ago when he was only 19, agrees: “I was often exploited to make other people’s work look like they had included a ‘youth voice.’”

A turning point came when McClelland realized he needed to take charge. “Eventually I learned how to turn the tables and empower myself while doing education and advocacy work in the community.” He became involved with a group of young people in Positive Youth Outreach and they started running their own workshops. “We recognized there was a gap in services so we researched the needs of youth living with HIV in Toronto,” he says. “We were empowering ourselves with up-to-date information about what our peers needed and taking control. Funders and community started to listen and realized that youth knew best how to meet their own needs.”

At the end of the day, McClelland says he does not feel disappointed about how he was treated. “Those experiences do not bring me down. I learned from them, and I hope the adults involved learned from them as well,” he says. “I was a person who ended up filling a void and being a voice where there wasn’t one before. Ultimately, my work has empowered me, and I ended up connecting with many other positive youth around the country. Now there are more of us positive youth becoming involved and that makes me proud.”

For Marco Gomes, the key to successful HIV services for youth comes down to empowerment and respect. “We need to focus our attention on youth and let them know that having fun is not a bad thing, but there are ways they can protect themselves and their partners from HIV,” he says. “They should have the liberty to get a condom without being questioned and we should provide information that will educate them. Youth need to get involved and be given proper training and opportunities, because young people are the best educators for themselves.”

Gomes feels strongly that positive youth need and deserve a voice—and that they can do it on their terms. “To youth I say, try to learn as much as possible and don’t accept it when people say you are not qualified to be a part of this or that. Being a youth leader doesn’t mean you have to be a poster child for HIV. It may mean standing up against stigma and discrimination and saying, ‘I’m a youth and I don’t think that’s right.’ That, too, is being a leader—bringing about change by talking to one person at a time. You can be a small leader or a big leader.” +

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Colleen Patterson, until very recently the director of communications for the Red Road HIV/AIDS Network in Vancouver, was Chief Youth Rapporteur at AIDS 2006.



The Keys to Serving Youth

CATIE’s youth liaison Sugandhi Wickremarachchi spoke to Jason Asselin, coordinator of Positive Youth Outreach (PYO), a peer-driven program with the AIDS Committee of Toronto (ACT), about what agencies need to do to best serve young PHAS.

- Get youth input into programming meant for them.
- Understand that identity issues are very important to young people.
- Tailor your offerings to your audience: one youth program cannot serve all youth.
- Create a safe space where confidentiality and trust are guaranteed.
- Offer psycho-social support and education to foster self-confidence and independence.
- Understand the specific developmental issues associated with infant and childhood seropositivity and know that perinatally infected youth confront different issues than those recently infected.
- Ensure a non-judgmental, supportive environment.
- Consider the range of literacy levels of youth.
- Be helpful in negotiating both health and social service systems.
- Let them be themselves; consider creating specific places and times during which only youth will be present.

