

Assessing the HIV/AIDS prevention, education  
and support needs of trans people  
living in Toronto

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## **Executive Summary**

In July 2004, at the request of the AIDS Committee of Toronto (ACT) in partnership with the Meal Trans Program at the 519 Church St. Community Centre, an HIV/AIDS needs assessment of Toronto's trans communities was initiated. Participants who self-identified as trans in some way completed an anonymous survey, did a one-on-one interview with the principle researcher, or participated in one of three focus groups facilitated by Syrus Ware, the principal researcher. Participants were diverse in terms of gender identity, ethnicity, income status, HIV status, and culture. Research was also gathered from one-on-one interviews with trans service providers and ACT staff members.

From analysis of the focus group, survey, and interview data, it became clear that many trans people knew about program and service options at ACT. While many had good things to say about its programs and services, some participants experienced several barriers to accessing these services.

It was also clear that the needs of these communities are great, ranging from issues of economic inequality, lack of access to appropriate and respectful health care, experiences of transphobia and isolation from the larger non-transsexual society in Toronto, as well as a general lack of support and advocacy. Participants emphasized a need for better access to health care, increased partnerships between ACT and local trans groups, agencies, and organizers, and access to trans-specific information about HIV/AIDS.

Participants felt that ACT was taking a good first step by consulting community members, but many felt unsure that the agency would take any concrete steps to address the issues brought out during the needs assessment. Additional concerns were raised about ACT's need for continued and sustained consultation with trans community members. Many participants requested that ACT maintain contact with community members to ensure a sense of ownership by trans community members.

Based on the data from this needs assessment, recommendations for better serving these communities include: training for ACT staff, board and volunteers; the creation (where appropriate) of trans-specific programming; expansion of gender-segregated program modules to better serve gender-free and gender-neutral clients; the further development of partnerships with existing local trans community groups, agencies, and advocates; the development of policies and procedures concerning trans people at ACT; and a dedicated effort to assess and develop a response to the needs of intersexed people in Toronto.

It should be noted that the participants shared extremely personal and intimate details of their lives during the research process. Participants routinely discussed their passion for working on the issue of trans acceptance and inclusion. Some group members traveled from other cities and towns to attend the focus groups. Some even brought lists of ideas on how to improve service. It was repeatedly stated that participants were involved in this project because of their deep connection to the issues discussed, and that they hoped to see their information used to positive and constructive ends.

## Introduction

Many of us have been taught that there are two distinct and mutually exclusive sexes, and two distinct and mutually exclusive genders. In fact, that couldn't be farther from the truth. People have explored the fluidity of gender, and the possible varieties of sexes for thousands of years. The rich histories of trans and intersexed people span the globe and human history.

Why is it that mainstream society insists on the acceptance of two genders, and two genders only? Where did this idea come from, considering the ample historical documentation of people who may now be considered 'trans' and 'intersexed' having been embraced or been accepted by a variety of cultures and societies?

It is important to note that people whose gender might not be defined 'female' or 'male' have existed throughout human history, despite historical and contemporary efforts to deny that existence. In truth, trans people have played important, even revered roles, within many societies around the world.

When, and how, did trans and intersexed experiences come to be marginalized? Social constructivists believe this 'constructed' system of categorization (female/male, feminine/masculine) is dictated to humans through social structures and the attitude of the dominant culture. While some cultures have embraced gender fluidity, most, sadly, have not.

The societal norms of these cultures are built upon an essentialist structure which dictates that there are basic, essential differences between female and male. These perceived *biological* differences between female and male typically support the hierarchical categorization of men over women, and of masculine over feminine. Essentialist beliefs have, throughout history, fostered hierarchies that reward those who uphold the values and rules of the dominant culture and punish those who challenge them — by the simple fact of their existence outside the male/female binary, trans and intersexed people challenge those values and rules, and have suffered for this.

However, evidence of multiple forms of gender expression, and of intersexed realities directly contradict essentialism. Trans and intersexed people have been marginalized or worse throughout history and through war and colonization, but they continue to exist. Their courage and perseverance pose a direct challenge to these perspectives.

So here we are. People are born with many different primary and secondary sex characteristics, and chromosomal combinations, and they feel an infinite number of different genders, but we have no common language or understanding of these experiences. Gender and sex continue to be reduced to a simple binary: male/female, masculine/feminine.

As a result people who identify outside of the realms of 'female' and 'male' are seen as beyond the pale of mainstream society, even though if every person allowed him or herself to be how they felt, we would see that most of them experience gender and sexuality as a continuum, and embody both 'masculine' and 'feminine' qualities. Even now, trans people tend to be viewed and represented in mainstream North

American culture as mentally ill, or worse, are ignored completely. Transphobia is a daily reality in our lives.

That said, we are witnessing a time of exciting change in trans and non-trans communities, as we rediscover lost histories, create more trans-inclusive spaces, and engage in mutual healing and growth.

## **Background**

In 2002, ACT began formally discussing trans issues, both internally and within the Women's Outreach Network (a network of Toronto service providers that includes local AIDS Service Organizations and other organizations serving women). These discussions revealed a need for professional development training on trans issues. In 2003, Kyle Scanlon of The 519 Community Centre's Meal Trans Program facilitated a Trans 101 Workshop for Women's Outreach Network members.

Working together, ACT staff Tania Smith and Chris Lau coordinated an internal information session on Trans HIV issues and risk factors. During this session it was recommended that ACT consult the diverse trans communities for further information on relevant issues. ACT was also encouraged to establish and develop a relationship with trans communities in the city.

A call for advisory committee participation was circulated through networks and list-serves to support a participatory approach. The Advisory Committee consisted of Toronto Public Health representation, trans community members, The 519 Community Centre and ACT staff representing education and support services. Committee activities included the development and circulation of the call for proposals; participation on the hiring committee; information, support and guidance; project and report feedback; and approval. Interviews were conducted with consultants selected from the proposals submitted, with members of the advisory committee participating in the selection process.

In June of 2004, Syrus Ware was hired at ACT to initiate and complete a six-month community-based research project designed to assess the HIV/AIDS informational, programmatic, and service needs of trans community members in Toronto. The results of this assessment would be used to inform program and service development both internally at ACT and at other agencies in the city.

## **Project Goal**

To develop relevant and appropriate partnerships, programs and services to meet the HIV prevention and support needs of trans communities in Toronto.

## **Project Objectives**

1. Identify HIV risk, education and service needs, and barriers to accessing services for trans communities.
2. Develop an action plan including immediate and long-term education and service development and integration.

## **Project Design**

- Literature review of trans sexual health research, services and issues and interviews with trans-specific service providers and front-line workers.
- Focus group recruitment.
- Three focus groups with trans communities and one-on-one interviews.

- Meeting with each ACT department.
- Analysis and report writing.

## **Methodology**

Data was collected from trans community members, trans-specific service providers and front-line workers, and ACT staff. Data was collected via one-to-one interviews with service providers and through a series of focus groups, one-on-one interviews, and anonymous surveys with trans community members. All interviews and focus groups were conducted by Syrus Ware and were audio taped and transcribed.

## **Data Collection**

The first stage of the data collection involved interviews with staff from a cross section of ACT's departments to discover what services and programming were currently happening at the agency, and to find out what staff saw as the current obstacles to improving trans access and ownership.

The second stage of the research involved one-on-one interviews with staff from agencies providing service to trans communities in the downtown core to discuss what services and programming they offered, what needs they saw regularly amongst agency members or clients, and what programming, services, and partnerships they would like to see at ACT, based upon these identified needs.

The third stage of the data collection was the most detailed. It involved consulting members of trans communities in Toronto to learn about their HIV related concerns, issues and needs; to determine familiarity with ACT services; to identify any barriers to accessing services; and identify appropriate strategies to meet community HIV service and education needs. This was done in three ways: an anonymous survey, one-on-one interviews, and three focus groups. All of these had essentially the same questions, and included the collection of demographic information.

Data was compiled and organized by themes. Meetings were scheduled with each ACT department to present relevant information and to determine short- and long-term program service and programming, with the understanding that the findings from the final report would be used by ACT staff in the development of future work plans.

## **Limitations**

There were some limitations to the project. Primarily, this was a huge undertaking given the time constraints. The entire project, from the recruitment of participants, conducting of focus groups, one-on-one interviews, data analysis, and report creation were undertaken by the principal researcher. A transcriber was hired to ensure that project timelines were followed.

A delay in the production of outreach materials slowed the recruitment of participants for the focus groups. The outreach materials were distributed widely to community groups and agencies, trans club nights and events, health clinics, universities, and media outlets.

Due to staffing hours, promotional materials were only distributed over a two-month period. This resulted in high turnout for the three focus groups in the summer, but lower turnout for one-on-one interviews in the fall, when the bulk of the outreach had ceased.

It should be noted that this research project aimed to look at the need of trans people in Toronto. The scope of the data collection did not include the needs of intersexed people. It would be extremely beneficial in future to connect with members of the intersexed communities in Toronto in order to assess and address how to better meet their HIV/AIDS-related needs.

## **Terminology**

There were many types of gender identities listed on the collected demographic surveys filled out by each participant. For the purpose of this report, *trans* will refer to the spectrum of people who identify with the trans experience; specifically, people who exist outside the boundaries of the dominant binary system for defining gender (non-transsexual male/non-transsexual female).

*Gender* is a way of categorizing people based upon several factors: primary and secondary sex characteristics, mannerisms, appearances etc. There are extremely diverse and divergent ways in which people identify their gender. Dominant culture suggests that there are only two genders that are acceptable: woman and man.

*Gender Identity* in this report refers to the way an individual identifies, or feels their gender to be, at any given moment.

*Sex* in this context refers to the physical anatomy of any individual. There are many variations of genitalia and chromosomal combinations, but dominant culture suggests there are two mutually exclusive forms of genitalia and of chromosomal combinations- and these are grouped into *female* and *male*.

The terms *non-trans* and *non transsexual* refer to people who do not identify as trans in any way; and are used in place of the exclusionary terms “genetic” or “biological,” often used to describe these communities.

*Gender free* and *Gender Neutral* are terms that refer to people who do not identify as a distinct gender.

*Transgendered* is a term that refers, in this report, to people who do not classify their genders as being within definitions of male or female as defined by the dominant culture. Some *Transgendered* people may identify as genderless, as a third gender, as both genders, or as something else entirely, to name a few examples.

*Two Spirited* is a term which many First Nations lesbian, gay, bisexual and transgender people use to identify. Indigenous Nations across North America have their own names for lesbian, gay and transgender people; Two-Spirit is more of an umbrella term that can

mean many different things, including anyone who challenges the boundaries of sex and gender.<sup>1</sup>

*Intersexed* refers to “anyone who is born with sex chromosomes, external genitalia, or an internal reproductive system that is not considered “standard” for either male or female”.<sup>2</sup>

It is important to remember that everyone who identifies as trans, or transsexual, or genderless, or transgendered, etc. will have their own definition of what the term means, and who the term refers to.

*Sex reassignment surgery* (SRS) refers to different surgeries to alter the body in some way (for example: breast implants, phalloplasty, chest reconstruction surgery, or vaginal construction.)

## **Participant Demographics**

A total of twenty one focus group/interview participants within the trans community participated in this study. A majority were over the age of 30. Please see the appendix titled “*Demographic Form – Research Participants*” for a breakdown of socio-demographic information related to participants.

Participants described their identities in diverse and individual ways. It should be noted that the responses for the description of gender identity were extremely divergent and creative. Responses ranged from gender-free and genderless; transsexual male/female and MTF/FTM; tranny, gender queer and transgendered, and simply male or female.

Several participants felt anxiety or frustration over having to choose one term to identify their gender, while others described wanting to be seen as female or male, with trans never needing to come into the description.

This divergence further suggests that the term trans may be an inadequate means of defining an extremely diverse group of people.

In addition to the diversity of definitions of gender identity, participants’ experiences of sex work, incarceration, working history and economic status, and HIV status varied. Just over half of study participants had worked doing some form of sex work at some point in their lives, and just under half had a history of incarceration or had come in conflict with the law.

Although HIV status was not collected on the demographics survey, some participants self-identified as being HIV-positive during the course of the focus groups and interviews.

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<sup>1</sup> [www.nwtwospiritsociety.org/history](http://www.nwtwospiritsociety.org/history)

<sup>2</sup> [www.isna.org/FAQ](http://www.isna.org/FAQ)

## **Trans people and HIV/AIDS: An Overview of the Issues**

There were several key elements that participants identified as increasing their HIV transmission risk, and, additionally, their ability to live healthy lives with HIV/AIDS. Participants' access to both community and healthcare services were greatly affected by experiences of transphobia. This lack of access impacted on overall health.

**“We have an alarming number of people that have HIV in our community.”**

Participants listed the following as increasing their HIV risk:

- Poverty
- Lack of access to safer sex materials
- Street life
- Not fitting into the gay or straight communities (isolation)
- Rejection by society
- General mistrust of the healthcare system.

Participants also listed these issues:

### **Criminalization of sex work:**

The threat and reality of arrest and prosecution of sex workers contributes to unsafe working conditions, and, coupled with the lack of consistent labour standards, and the evidence of potentially being paid more to have high-risk sex, increases their risk of contracting HIV. Although some focus group members felt that sex work itself led to an increase of HIV in trans communities, others cautioned against generalizing about sex workers, and against making assumptions about who does or does not practice safer sex when working:

**Yeah, but most sex workers such as myself... I always make sure I have condoms. One of the other working girls will come up to me and ask me if I have condoms. Yes, certainly I have condoms. I'll give them two or three condoms. Here you go.**

**Unfortunately, you will get paid more if you do it unsafely and that's the way to [get] infected but you know that the almighty dollar in today's society is what talks to you.**

### **Lack of relevance of safer sex materials/guidelines:**

Participants noted that existing safer sex materials and the instructions for using many barrier methods are often gender specific, and thus pose problems for many trans people. Information may or may not be relevant to trans body parts.

**Female condoms do not work on transsexual women because we don't have a cervix to hold them in us... There is no information for us.**

**These [safer sex kit] materials here on the table...like these safety things. You know, they [the safer sex kits] make me go what is my gender? And it really freaks me out.**

In general, HIV prevention materials and messages are not geared towards trans anatomy and bodies, and this leads to uncertainty about product usage. Prevention messages often lack tips on negotiating the use of safer sex strategies and this inhibited its use.

Lack of harm reduction information related to hormone use:

Participants agreed that many trans people may never choose to take hormones, and that there are often many barriers impeding access to hormones. And yet, taking hormones is a reality for some. Unfortunately, there is not enough information on harm reduction specific to hormone use, and, coupled with a lack of access to intramuscular (IM) needles (a specific gauge of needles used for injecting hormones), the result is often the reusing and sharing of needles.

**Some of us are using needles and injecting ourselves with hormones and I mean there are some of us who obviously have access to clean needles and there are members of our community who may not for whatever reason you know have that access and that's you know a big issue.**

**The piece on needles here doesn't speak to injection of hormones. It just talks about drugs injection through drugs. So that's again another... something absent.**

Lack of access to hormones/IM needles:

Participants also talked about the barriers to accessing hormones, resulting in sharing hormones. This in itself might not pose a problem, but coupled with a lack of access to harm reduction materials (in particular access to IM needles), results in people sharing unclean needles, i.e. needles maybe reused and hormone samples may become contaminated.

**Some of us are sharing hormones.**

**We need ...access [for] people who do want to go on hormones. Either it would be good to for people who can't necessarily afford it or have a health plan to have free access.**

**...getting hormones...not through like a doctor or under medical supervision but from your friends, [the result is] the lack of access to materials to inject hormones.**

Negative attitudes towards drug use among service providers:

Participants reported discrimination in the form of highly negative attitudes towards drug use from service providers at several local community agencies. This impacted on their willingness to access services:

**People just don't go to organizations because they have negative experiences. And so they don't have access to condoms, needles, information on how to be safer.**

### Negative experiences with the healthcare system:

Transphobia had a profound impact on several determinants of health covered within this project. Negative experiences with front-line staff, nurses, doctors, and other health care personnel in many cases resulted in trans people being unable to access needed health care- in some instances even in cases of urgency:

**The answer is most of the health care professionals don't have the research, hasn't been done, its not about to get done. You know in so many ways where there is information needed we're better going to each other than.. turning to the health care professionals, who don't know, and are often not ready enough to say "I don't know."**

**I've had experiences where I have gone in for something else and to a health care practitioner just recently and told him that I was trans so that I'm kind of in charge of saying that. Then right away he said to me "Have you had all of the surgeries," So that kind of weirdo interest in it ... but anyways negative experiences with health care professionals. All kinds keep trans people away from just general health stuff. I think around HIV stuff as well to be someone who is HIV positive and trans is again will be made the weird sort of freakish interest in or being treated like a freak around you. Being trans and a lot of assumptions to think they know and that there are only two kinds of trans people just transsexual and transvestite, not understanding other manifestations of it.**

### Segregation of medical services by gender:

Some participants expressed frustration with the separation of medical services into two genders — stating that this often impacted on their ability to access service:

**Well, there is always the joy of calling Hassle Free – do you call Hassle Free on a Women's day or on a Men's day? Will someone please explain this to me?!**

**You have this idiot choice, do you go when they have got the doctors and the access to equipment that work for female bodies or when they work for male bodies ... how are you supposed to handle this? That's a piece that really needs to be shifted.**

### Lack of access to information:

Focus groups revealed that trans people are sometimes choosing not to ask for safer sex information from healthcare professionals because they have had past negative experiences with this process due to transphobia:

**I think from other trans people for referrals, if they know one good doctor or one good thing we go to our own resourcefulness. I think that people maybe share what they know about or they are just forced to go and be treated like shit. ...Certainly, if you know of a place where they are going to respect you and respect your name and your gender that you present and all those kinds of things about yourself, that's where**

**people will go. But I think a lot of times people just aren't going anywhere. They aren't getting anything at all.**

Participants also discussed avoiding testing for sexually transmitted infections (STIs) and HIV for similar reasons:

**But the problem is that not everybody tests. Because many people don't know what to do. They don't speak the language or they are afraid to be stigmatized or they don't know what kind of services that are around for them.**

Viviane Namaste's "HIV/AIDS and Female to Male Transsexuals and Transvestites: Results from a Needs Assessment in Quebec" also reported difficulties accessing services due to transphobia.<sup>3</sup> One participant referred to Namaste's research during the focus groups:

**I think that trans people ... from much of the literature I have read will locate themselves outside of services. To quote Namaste: People have problems in accessing services for like the pronoun use so people just don't go to organizations because they have negative experiences. And so they don't have access to condoms, needles, information on how to be safer.**

#### Misinformation about HIV/AIDS:

Some people mentioned relying on information from friends and the Internet. Although this was not always the case, some participants felt concerned that they may be getting misinformation. At the same time, this was still reported as a preferred method for getting information:

**Yeah but what I'm saying I ask friends what they think. Like friends I know what they think and it might be misinformation. I'm not really sure and I try not to take their word as law.**

**Let's see. I go to the Internet, I think. I go to friends and people I know who are like sexual health educators or trans people. I guess I go to my own mind and maybe what I know, what I think, but yeah, otherwise I think on the Internet — places like I've been to some sites in San Francisco where they have... and in New York ...where they have trans men HIV prevention and health projects and stuff there.**

#### Lack of research focused on trans people living with HIV/AIDS:

HIV medications are tested on non-transsexual people, and there is very little information on reactions of HIV medications on trans bodies. There is also little to no information on interactions of HIV medications with hormones or SRS.

**They've also got to find a way that they can start finding information on medications that aren't going to react with us. They test them on men. They test them on women. They don't test**

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<sup>3</sup> Namaste, Viviane "HIV/AIDS and Female to Male Transsexuals and Transvestites: Results from a Needs Assessment in Quebec", 1999

**them on us. I'm sorry but our systems are not like a man's and not like a woman's. So we're not going to react to them the same way that somebody else can.**

**I mean they are just coming out with it now if you're HIV positive some of the hormones that you can take are very bad for you because you can have a major reaction to antivirals. And one of the big things that they try to get you off of is the hormone pill because a hormone pill goes through your liver twice within 24 hours but with the injectable it goes through once in 30 days.**

Trans surgeons may not know about HIV/AIDS issues, and this may result in them denying SRS to HIV-positive trans people, based on this lack of information. Conversely, HIV specialists may not be able to inform trans surgeons on HIV/AIDS due to unfamiliarity with trans surgeries and general health concerns.

**[We] need to have doctors who are well informed, at the very least who aren't transphobic or but who are ideally informed about different trans identities and the interactions of things again like everything from hormones and drugs and HIV medication and so called street drugs and that kind of stuff.**

**Nothing is tested on us. They don't even test hormone therapy on us.**

#### Social isolation:

Transphobia and misinformation can lead to isolation. This is exacerbated by divisions and marginalization within trans communities.

**The thing is, in trans communities what it is ...pretentious... People don't fit into the trans community. Like you've got sex workers, you've got [people] from all different backgrounds and people aren't fitting in.**

**I don't think that there is a trans community.**

**The impression that I have is that the LGB community has, at times, contributed to the ignorance and intolerance. ...I hang out with a lot of women that associate with being gay and they don't know anything about transitioning. Even though, well, the idea is that most LGBT community are in the same boat and yet many people on the boat aren't even aware of what the other side of the boat is going through. I think that's a big thing that needs to be looked at.**

Isolation is often a trigger for depression and despair, and this may lead to increased risk taking as people lose hope.

#### Lack of potential romantic/sexual partners leading to HIV risk taking:

A perceived or real lack of trans-knowledgeable partners may lead trans people to take risks in order to keep partners.

**In terms of increasing risk factors tremendously there for FTMs (Female-to-Male) who are desiring men... its so hard to find partners — the temptation to go ahead with unsafe sex is very much higher”**

#### Sexual assault:

Experiences of sexual assault contributed to some participants understanding of HIV rates amongst trans community members.

**We have harassment and a lot of rape.**

**We have a lot of assaulting.**

#### Economic needs:

Economic support, or the lack of it, was discussed at length. Participants felt that there are limited employment options for trans people due to transphobia. In addition, participants felt that this, exacerbated by the cost of SRS, lead many trans people to live in economically disadvantaged positions:

**[Some issues for trans people are...] Well, both lack of education and lack of employment... high rate of unemployment and so although we have people with education, [ a lack of] access to services and information**

**I mean before I started transitioning I had an upper class lifestyle. I had money. I had everything the moment. I started I dealing with this and all that stuff magically disappeared.**

#### Personal identification:

Processes requiring ID, including travel, employment, healthcare, housing, and social services were affected by systemic transphobia. Participants discussed the expense of name changes, restrictions on changing gender identity on government ID, and the need to replace ID as one transitions.

**...or the picture doesn't look like you anymore.**

**People go to walk in clinics a lot because places where you know not having ID or an OHIP card is maybe not going to stop you from it. Certainly, if you know of a place where they are going to respect you and respect your name and your gender that you present and all those kinds of things about yourself that's where people will go. But I think a lot of times people just aren't going anywhere. They are getting anything at all.**

It should be noted that when asked about rates of HIV/AIDS amongst trans people, responses varied greatly. In fact, there was a tremendous response during the focus group for trans-identified women. During the focus group for trans-identified men and transgendered or many-gendered people, participants felt uncertain about what the HIV/AIDS rates of infection and pressing issues were for trans community members, although participants extrapolated what they could see as posing an increased risk.

Participants regularly noted the lack of research on trans people and HIV/AIDS along with highlighting the need for more thorough research in these areas.

The Hepatitis C virus was mentioned by a few participants. Participants discussed liver toxicity as it related to hormone use. It should be noted that many of the above mentioned HIV/AIDS risk taking behaviours are also risks of transmission of Hepatitis C.

## **Perceptions of ACT**

Participants stated that they generally enjoyed ACT's proximity to the queer community and downtown Toronto. There were various levels of awareness of ACT's programs and services. ACT's visibility, its closeness to the subway, and its prominent signage were also mentioned:

**I think the location is great.**

**I know they have this like program with really hot pamphlets.**

**I thought they only gave out condoms.**

**A place where I can get knowledge, referrals and services I may need and it's kind of open to people with different experiences.**

This needs assessment was the first encounter with ACT for many participants. The research was seen by many as a first or only step that ACT has taken in reaching out to the trans communities

**They don't [serve us]... In order to have an issue with the way they serve us, they would have to service us.**

**I think this focus group is the first thing I have seen as an attempt to at least find out from the trans community what is lacking or what's needed.**

In almost every focus group and interview, participants expressed anxiety about what ACT would do or would not do with the recommendations coming out of this report:

**I think it's important that once they hopefully actually start putting this stuff into action that they don't just assume well we asked trans once so we've done our job. And they actually keep coming back and checking in with the community making sure, asking what they think and making sure they've got it right. I don't want this to be like we paid trans for their opinions so we can just go off and take it now and roll with it.**

## **ACT: What's working**

Participants discussed both the positive and negative aspects of ACT's current programs and services. When asked to define ACT, group members described ACT as:

- An AIDS network;
- A place to get knowledge, materials, and referrals concerning health promotion and HIV/AIDS;
- A powerful, long-standing, large organization that has innovated in the area of HIV/AIDS;
- An agency with a lot of credibility and a very high profile;
- A support for people living with HIV/AIDS;
- Open to just about anyone coming in to find out more about HIV/AIDS, and get relevant materials;
- Essential to their survival.

Participants had this to say:

**I don't think I would be alive today without this place.**

**I would say that when I have called ACT or contact anyone at ACT to help out with either an event or provide a service they have been pretty helpful. Really pretty accessible and good follow through in terms of the stuff that they say they can provide.**

**They do a lot of great work and they work really hard to meet the needs of a lot of different people.**

There were participants who reported very positive experiences at ACT.

**Yeah, I guess, y'know, my experience with ACT has been positive and hasn't been discriminatory. I've had a lot of friends who worked here.**

**I've had good experiences. I'm sad when I hear people have had bad experiences.**

### **Trans people who volunteer at ACT**

Some people mentioned their volunteerism at ACT. It should be noted that many people mentioned a desire to increase the number of trans volunteers, specifically trans volunteers on the front lines.

**I volunteered here for different things, like we give out the books and get furniture and different things, and give out water when they have the walks coming up in the next few weeks. A lot of different things. I have lost count over the years.**

**One thing that they did that I know was good was they had a workshop for like the staff or volunteers and there was a trans 101 workshop. So basically, it was to help staff be more sensitive.**

## Support

Support services were among the most-discussed services. The perception of the support offered at ACT varied greatly. Some felt that ACT offered very good support services to people with HIV/AIDS and those concerned about HIV/AIDS.

**The counselling is great.**

**I like that you have outreach and you go around giving counselling. To me that's probably the number one thing I'm concerned about.**

## Resource and Information Dissemination

Participants spoke highly of ACT's harm/risk reduction messages in its pamphlets and brochures:

**I found the material to be good in terms of, even talking about like... mentioning different kinds of drugs. If you're doing it, y'know, definitely you could see someone was doing it from like a harm reduction perspective. Not just don't do it, but if you're going to do it here's how to do it safely, that kind of stuff.**

Participants discussed ACT's role as an information provider:

**[ACT is] a good place to get safer sex information or supplies either for personal use or if you are doing an event. I always find it pretty helpful in terms of that.**

**I do like a lot of their professional material. It would be nice to be included in it...its better than a lot of crap that's out there.**

Referrals ranked high on the list of services that participants accessed at ACT, that people were in need of, and in which people wanted to see continued expansion:

**A friend of mine said that he got helped out with getting [in touch with] a masseuse, a massage therapist.**

**I would say that I have come to ACT for referrals in some of the work that I do and where I work, my profession, my day job.**

## Multiple languages

ACT's programs and information offered in multiple languages was frequently mentioned. Participants had this to say:

**Yeah, I've seen material at ACT in different languages which is good because Toronto is such a diverse community. It's good that they keep up that.**

## **ACT: What's Challenging**

Participants had a lot to say about challenges ACT needs to address, including the perception of trans invisibility at the agency.

**Well, I enjoy being here. The services are great. The people are great. It's just that, well, for myself, I find I'm not seen as a transsexual. A great example of this I've been referred to as a transvestite, a guy in a dress. But nobody really gets it... this is how I feel at ACT. I am here but nobody really gets it.**

### **ACT's Focus**

As to why some people had not used or accessed ACT's programs and services, people discussed having the perception that the agency only served a specific community or set of communities:

**I think the perception for me is that it serves mostly gay males.**

**Like the south Asians hanging out here at one agency, east Asians hanging out there at another and all the white people going to ACT. So it's really, really quite segregated. But that's not to say that they're doing all negative work. Of course, it is really obvious that they're doing like really, really positive work, which is necessary. So what I think there needs to be some cross-cultural thing built [into their programs].**

### **Trans people at ACT**

Of the participants who discussed using ACT, there were varying views. Although some participants who used ACT services discussed the importance of the agency in their overall survival, individual experiences with the agency were quite divergent. Some members spoke of extreme instances of transphobia and a general lack of knowledge of trans issues:

**Many people are afraid [to come to ACT]. They don't want to come to a situation because they don't want to have that kind of [transphobic] confrontation.**

**My thing is like a lack of acknowledgement of who people say they are, and then based on that, you might not be able to access certain things that you need.**

### **Experiences of transphobia at ACT**

Of participants who had used ACT's services, many listed experiences of transphobia at ACT from the staff, volunteers and other clients:

**I used a service here a few weeks ago, and the guy who runs it is really good but I had an extremely bad problem with the [volunteer]. He continued to call me "he." I told him I was transgendered. I called him back the next day and he did it again... I got pissed off at him at this point and called him an asshole and hung up on him and ended up sitting and thinking,**

**how am I going to get [what I need]? He turned around and said to me “whatever, you people should not be here, you should be eliminated.”**

### Structural Issues at ACT:

The format and organizational structure of the agency and trans participation within this structure was discussed at length during data collection.

**I think they need to drop a lot of assumptions — just because they may have dealt with one person who identified as a trans male or trans woman doesn’t mean the next person who identifies with that is going to have the same thing or is going to even look at that identity as the same way. Just even if they are using the term or whatever word so just...look at the person as a totally new person.**

**I have also referred people to ACT but I’m a bit weary about referring trans people here because I don’t know. It hasn’t been clear whether ACT has thought stuff through.**

In addition some felt that the structure of gender-segregated programming created a barrier for gender-free, transgendered and non-gendered people:

**It seems to me like a lot of their programs and activities are geared — at least the ones I’ve been exposed to — are for usually for like for women or men. And so, I’m not going to... I don’t go to anything that is gendered segregated like that really for obvious reasons.**

**I mean they need it open. You may not know it they need to pay attention to it. Actually need it out in the open. They have men. They have women. What’s wrong with saying trans?**

### Programs/Services

Participants generally did not know of or feel that ACT had any programs or services *specifically* relevant to trans community members:

**I think that while they are really open to like just about anyone coming in, I don’t think that there is anything which specifically says that I could find information here that affects me...or helps me out with any situation that I may be in. Like I have never figured out how I relate to it.**

**I have often wondered how ACT and I fit together and I have... a lot of questions... about what ACT has to offer the trans community — different trans communities actually.**

**Y’know, its funny, because I think one of the reasons I haven’t accessed ACT services is because I don’t think that they would have anything for me. I don’t think that if I, as a transsexual guy, was looking for information on my risk of HIV... y’know, but everything from safer sex materials [to] I don’t, know like how my body has [been] changed by hormones and how that might affect like everything from to y’know STD’s and therefore, HIV. I don’t think they have that information. I don’t think that they would have them, y’know, anything that would speak to me. I don’t think so.**

## Support Issues

Many participants identified practical support as a need. Misunderstanding of trans realities often resulted in service providers – not just at ACT but elsewhere — not being able to offer practical support effectively. Some group members had experienced confusion and general mistreatment when accessing such services at ACT.

**I find that the... program was good in terms of what it did.  
I just found the attitude ...because it's mostly men who go to it.  
For me, it's a question of attitude rather than the people.**

**Whoever the staff or volunteers who run it need some kind of training so they can know to identify us how to treat us [for] who we are rather than just seeing a man in a dress.**

Due to experiences of transphobia, both on an individual and systemic level, many participants expressed feelings of isolation, frustration, and, in some cases, anger.

Some participants knew of ACT's support groups and services, but they felt that the groups may or may not have been suitable for their experiences.

## Safer Sex Material Distribution

When asked to speak about what ACT offered, most contributors highlighted the distribution of HIV prevention and safer sex materials. Predominant was a sense of frustration and confusion about what prevention materials trans people should, would, and *could* use. Participants noted an overall dissatisfaction with their choices of safer sex materials.

**The safer sex material is not in any way ever aimed at trans people... or even sensitive to issues around trans people.**

**It's really hard to find like packages. Out of all of the packages. I've gotten from ACT like in the last four years, I think one or two of them have had a glove in them. The rest of them are all condom packs. I've hardly had only one glove and it wasn't even from ACT.**

The division of information packages and safer sex kits into female and male packaging posed a problem for some participants.

**They're dividing them (safer sex kits) on these gender lines. But the truth of it is, that a lot of gay men use the reality (female) condom ... and a lot of women ...use condoms for various things so it isn't even necessarily...it's not even necessary to divide them . You can make one big pack.**

**For me, it makes it harder to find the information but specifically on a level of like, I can't explain not because it's hard... to go and... find these materials to translate and then I just feel really frustrated or tired.**

### Pamphlets and Information materials:

Several participants reviewed the existing literature/brochures offered at ACT on issues of HIV/AIDS and safer sex:

**Now, there *is* transgendered in here. If you are one of those transsexual people who don't like the word transgendered that will certainly throw you off. The literature doesn't speak specifically ...in this other pamphlet so I think it needs to be amended to include trans language. And I'm not up on sex as a trans person because I've been limited experiences but so I'm not an expert on it. But here it says very clearly that women have vaginas ...now that's not necessarily true if you know much about the trans community and the man's penis, so like, I mean, that kind of language doesn't speak very well to the trans community. It needs to be... you could add something there. There is no pictures of trans people in here unless they are passing really well.**

**Do any of them [brochures] mention Trans?**

### ACT Website:

Participants talked at length about using the Internet as a resource for gaining non-judgmental information. Many felt that the Internet was an invaluable tool for meeting and sharing information with other trans people. ACT's website was mentioned.

**As a trans person, I know ACT is there and I've been on the website but I haven't actually found a use for ACT. So I'm not saying that's a bad thing but it's one of those things where there's an organization that is so close and yet so far away at the same time.**

### Publicity campaigns and events:

ACT was seen as a public agency with a high profile. Participants did not feel the promotional materials and media outreach spoke to trans community members, reflected their experiences. Nor did they promote the idea of trans people as part of ACT.

**For me, it's mainly like the posters and such. Like a lot of the posters, like those ones over there – it's like very specific communities and I don't really see myself represented.**

**Even in terms of some of the materials produced, we all know that HIV/AIDS affects, you know, everyone — all communities. I really can't recall a campaign that even focused specifically on trans men or trans women.**

## **How ACT can be more effective?**

### **Structurally**

The need for increased trans staff at ACT came up in each focus group and interview. This was seen as an important step in increasing a sense of trans ownership at ACT

**I think there should be some staff members who are transgendered or transsexual to show we are represented... on the staff or board.**

**If there were trannies that worked there, that were in management, that were involved in the designing, y'know, and implementing of programs. If there were policies that could address if there were incidents of transphobia and there [was] a process as to how you could address that.**

**I think to be visually represented is really important. Whether it's our bodies on posters or whether it's signs that have the words trans in them, hiring trans staff – like all of those things.**

Trans volunteers were also seen as necessary to increase ownership at ACT.

**Maybe even get trans volunteers for activities - something like that.**

Others discussed the format of the agency, seeing a need to revamp some organizational practices in order to better meet the needs of trans clients:

**They need to have like trans peers, who are doing health education, counselling and support and that.**

### **Policy/Procedures**

Participants felt the absence of written policies and procedures for trans ownership and involvement at ACT resulted in a lack of trans staff and few trans volunteers, and a general increase in experiences of transphobia at the agency:

**There should absolutely be an internal policy in writing or a manual that can be consulted.**

### **Training**

Training was discussed at length in every interview and focus group. Participants felt that improving the culture or environment at ACT to be more trans knowledgeable and accessible was important. Training should be for staff, management and volunteers – including the Board of Directors.

**I think that they should have a 'trans 101' workshop.**

**I think that the important thing for somebody who is training somebody is asking "How would you like me to refer to you" I mean ... in case that the person is a noticeable trans....**

**Trans people, transsexual and transgendered people should be part of the**

**training... So, that the first time the staff meet someone or who is on the telephone or when they come in for service they've already had some experience.**

**Back on the training ... this training [shouldn't be] for just front line staff but for management at all levels and for board members. So board members can't escape this training. No, just because, I mean, the decisions come down from all different layers so it's important that the training happens at all different layers.**

### Practical Support

Employment support and counselling and computer classes for trans people, and a clothing bank/swap for people in transition, were discussed. Participants felt that help with practical support would help trans people in many ways, including giving economic support to the community and helping with expensive process of transitioning and having to get a whole new set of clothes and accessories. Some of this might be programs implemented at ACT for trans people living with HIV/AIDS, or created in partnership with other agencies.

On employment support, participants had this to say:

**ACT could create opportunities for trans people to get experience for their resumes to get volunteer experience or even public speaking workshops and what not. So that's something, y'know, that could be mutually beneficial because a lot of trans people need experience to get higher paying jobs.**

**I'd go for economic support because I think that some of the people would have more support economically.... As well as if they had psychological and education support because I know some of them are out there because they need to get that money.**

A clothing bank, clothing store, or clothing swap for people in transition, and those needing economic support were seen as much-needed, positive supports.

**"I think that [we need] a clothing store for transsexual and transgendered people"**

**"I think I'd like to get a transgendered clothing store."**

**"[We need]... some are professional quality so people can get work."**

### Outreach and Publicity

Participants seemed unanimous that ACT should undertake a campaign that speaks to trans communities:

**I think that at this point because there has been nothing said or it didn't seem to me that there was any kind of attempt made, I think that they would just have to kind of for a short while do some kind of major campaign or something like to balance that off. ...maybe do a specific thing for like one period like do a heck a lot of it – you just a sort of initial welcome thing and even like signs would be cool – like a Trans positive**

**space would be nice**

**Advertising [the fact that ACT serves] trans people and stuff like that. A visible presence of some kind of services, otherwise what's the point?**

Campaigns of awareness and outreach should also be partnered with campaigns about HIV/AIDS and trans communities and prevention messages amongst these communities:

**I remember a few years when the campaign was called Welcome to Condom Country", the ride safely. That was a good campaign. Unfortunately, it was a very gay male focus. I think a campaign with things like that but with a little different ...maybe one gay model and then another Trans probably. That will actually create more the idea that this is really is a face that many people are kinda threatened.**

### Resources and Information

The need for respectful and knowledgeable referrals and information was frequently mentioned.

**A list of medical professionals, doctors and dentists, who are trans positive — not just in words but in actual actions — for referral would be good.**

**The trans project in Vancouver recently put together an on site list of all the trans positive doctors and practitioners for like everything from G.Ps to y'know physiotherapists.**

**Information on therapists, psychotherapy or even someone as simple as a massage or acupuncturists who are going to be you know sensitive to Trans issues or least aware. You know, that kind of information.**

### HIV prevention issues and trans people

Safer sex materials that are specific to trans bodies and identities were seen as lacking. This included both the specific materials used for safer sex, along with info kits, flyers, and packaging. Participants wanted to see ACT initiate safer sex information and packaging that would be more reflective of trans needs and issues. It might be possible for ACT to partner with other organizations (such as The 519) to produce these materials

**...maybe a safer sex... either campaign or even a supply package that actually has either trans people on it or in terms of a picture or poster inside of it... or even mentions, you know, trans people in some way.**

**Better safer sex materials. They need to see outreach materials and education materials that reflect their realities, that show them like us in different ways**

**Respectful and informed [materials that talk] about hormones, that know about different ways you have safe sex and what's risky and what's not. And how y'know the tissue for ...particularly a transsexual is that is changed by the hormones that is susceptible to everything from**

**tearing to picking up something.**

Participants also felt that materials needed to be distributed at locations where trans people congregated or accessed services. :

**I was thinking maybe the distribution of pamphlets and maybe being distributed to different clubs and The 519 and places where the trans people are gathering. And I think would probably be a good way to outreach as well.**

Participants discussed the phenomenon of tucking, packing, binding and other such practices. Group members wanted information on how to do these practices in a safer way.

**Binding 101 for trans guys or access to you know if you pack, information about packing cocks — that's again you know a lot of people might get that information from someone they know or on the internet but if you don't have access to any of those things.**

**Certain sex, certain kinds of sex... like ways... like actual physical acts and also different body parts, different genitals and that — I think are specific.**

### Supportive services

Participants listed support as one of their most important needs. In addition to HIV/AIDS-related supports (including a support group for trans people living with HIV/AIDS), participants indicated the need for support in areas such as:

- Affordable/accessible counselling for trans people
- Support services for children and families of trans people
- Support group for trans people doing sex work
- Respectful support and mentoring for people who are 'transitioning'

Some participants felt that ACT was in a good position to help trans people get access to this kind of support. The creation of referrals to trans-knowledgeable therapists and counsellors, partnerships with local trans support groups, and the continued support for trans-specific training and education for ACT staff were all requested by participants.

Many participants wanted to see a support group for trans people living with HIV/AIDS:

**One of the things that probably will be good probably is open a peer support group here in the ACT building for trans people who are HIV who are actually discussing how better ways to take care of their bodies.**

**Something you can do easy... I'd go with the support group. You can do that tomorrow. You can send out flyers. You could turn one of the focus groups into a support group but that's the easy thing.**

### Partnerships

Overall, research participants wanted to see an increase in partnerships amongst AIDS service organizations, and amongst trans service providers, and between the two groups. Some felt that the specialization and individuation of agencies coupled with the lack of strong partnerships, resulted in large gaps in service and programming.

**So what I think there needs to be some cross-cultural thing built. So they do joint things, joint ventures and that's important...I think...there [should be] links across organizations instead of just saying, "okay now we need to start a new program that deals with this specific need and new programs that deal with that specific need. Those needs can sort of dissipate themselves. The ones that are like on the bottom rung of the ladder, if there all isolated, they will require a lot of activism to get something like that to get started**

## Related Community Services

Several participants listed needs that were neither directly related to their HIV issues nor to ACT specifically. Advocacy in these areas could be taken on by ACT, in conjunction with health centres, community agencies, other AIDS service organizations, and community groups or coalitions.

### Accessing supportive services in Toronto:

Group members discussed the necessity of accessing support and services. The lack of adequate, trans-knowledgeable, and respectful counsellors, therapists, and support staff throughout the city was noted.

**It's difficult to find a therapist or counsellors that don't see you as a freak from the beginning. Like I just felt like a few years ago... I sought counseling. I went counselling shopping kind of... It was almost like he started off y'know... you okay with the trans, the S&M thing or is any of my thinking making you think I'm a freak. If they do, then we can't really have another discussion yet you know what I mean. I probably went to three or four or y'know a couple of times because they are so like y'know so excited to have such a strange person in front of them that it's like a learning experience for them.**

**Yes it's like extra impossible where I live because I have to go to one end of the city to the other and to a whole other city. Because like since I heard the word tranny its like what ... "how do we deal with you," Well if you don't know, goodbye.**

Others discussed the need for education and training for support service providers – both within AIDS organizations and within other social service organizations:

**One of the issues that I have dealing with counselling and people going to therapy is basically the fact that the many specialists — psychologists, psychiatrists or crisis intervention people — they sometimes mistreat the transgendered client. And then they excuse themselves by saying "Well, I don't know nothing about this." I mean that is unacceptable for somebody that is supposed to have the training to deal with our community.**

**It is not our job to train the doctors or the organizations, because you know, if you go in with a broken hand or some sort of symptom, they open their book and look it up. They study it... but when it comes to transsexuality for example, "oh gee we don't know anything about it. We can't help you." That is not a good enough excuse. They need to go and do the research. They need to be trained.**

### Issues related to children and families of trans people:

Still others wanted to see more support for children and families of trans people in the community:

**I have a daughter who just turned 25 and I'm interested in [how] the young people in our families deal with it. So if they could have**

**support groups for themselves. Because I know my daughter thinks she is the only one with a transsexual parent and I know she's not and others in the group that are my age and older or younger and who have kids are concerned. ...And I know we have it in other groups such as AI Anon and other things. There is support for them so they don't have to feel they are the only child with a parent...**

**[I want] A clinic where you would not only have access to medical facilities but also counselling and therapy... to outreach to children, to families. Just a centralized place that has information, that has counselling, that has medical services and is trans-positive.**

### Bathroom access

Access to both gay men's bathhouses and the Pussy Palace (an annual women/trans bathhouse night held at a men's bathhouse) were discussed. Participants saw a real opportunity for ACT to take a leadership role in advocating for trans access and training on trans issues in bathhouses in general. On the Pussy Palace people had this to say:

**I think there can be a flip between being quite fetishized and being quite unwelcome. I think that's part of the difficulty in queer, in lesbian community as a whole. There's that double-edged piece.**

**The last one that I went to, but I know a number of trans men that wouldn't go.... to a women's bathhouse and one person said to me because they felt that if they came in with a beard... they almost had to like qualify "yes I'm a man but a I'm a trans men" ...to say why they were there almost and ...they didn't necessarily feel that it was a welcoming space per se even though it may have said so in writing. But there wasn't anything in the women's bathhouse material, there wasn't any pictures of any trans guys that kind of stuff that would say yeah, that you are really welcome.**

One participant described trans experiences at men's bathhouses as this:

**It's a roaring lack of welcome with glorious exceptions.**

It was clear that dialogue and community action on this issue was desired and supported.

**Somebody at the 519 put on a thing a couple of years ago around access for trans people in gay male bathhouses... I don't whether it was ACT's or somebody else's. It was a good meeting, an excellent meeting.**

### Sherbourne Health Centre:

The health centre at 333 Sherbourne St. was discussed in every interview and group. Some participants felt that the health centre was a great support to trans communities while others mentioned disappointment with its processes, healthcare staff, and access to hormones and SRS referrals.

**I'm very happy with the Sherbourne... the only thing I would add to them would be more specialists. . . . Instead**

of having to go somewhere else to see a gynecologist, or whatever, to have him in-house.

**My impression is that they put a lot of emphasis on trans health care and that when they were developing the plan for the Sherbourne it was clear that they wanted to be very trans-inclusive and they wanted to fulfill a lot of the services that had been left by the Clarke.**

**They do duplicate some of the services from the 410 at St. Mikes'. The health care that I receive from them...I get the impression for the 410 that it's less "tranny tranny." We're here to support you. But I feel supported as just another client as opposed to you're a tranny and we're gonna support you. You're a person we're going to support you.**

**I've *heard* some bad things about some of the doctors at Sherbourne. I have my doctor there but I've heard things ... [from] trans people and non-trans people.**

#### Hassle Free Clinic:

Hassle Free was discussed by some participants. Many felt that the separation of services by gender lead to frustration and confusion about when they could access services.

**Well, there is always the joy of calling Hassle Free – do you call Hassle Free on a Women's day or on a Men's day? Will someone please explain this to me?**

**And just to stay I know that Hassle Free is not ACT but to just stay with Hassle Free and then you have this idiot choice, do you go when they have got the doctors and the access to equipment that work for female bodies or when they work for male bodies and — how are you supposed to handle this ? That's a piece that really needs to be shifted.**

#### Trans Advocacy:

Advocacy was seen as an important area of need. This included educating SRS surgeons on issues of HIV/AIDS, advocating for improved bathhouse access, and taking a public stand in support of trans rights.

**Educating doctors for psychological support as well. I think some of the doctors — like when I first got my doctor, he was just starting. But his practice is bulging with a couple of other doctors. I know so there's more need to educate doctors because more people are speaking up and coming forward.**

**Maybe it would be good to see ACT, maybe, either send staff or volunteers supporting a demonstration, be it a demonstration for sex reassignment surgery or be it any kind of trans event. To see actual ACT volunteers or staff there, that would be good.**

**I think it's really difficult to live within my trans body. I think anyone in this room can say... I've gone to an FTM group down here in the 519, and I don't see. . . I do not see very [many people] out there saying, y'know what, you**

could be in a woman's body and feel like a man, feel like you have a dick... and not take [testosterone] and not have surgery... I don't see... that you could live in that body without it and that's also an option...I go to the groups and it's "how do you find the doctor to change...to change", but I don't see "hey it could be difficult, it could be hell, it could be all that and it's also a possibility to not take "t"...I think it's a big problem, and ...I don't know if its ACT's supposed to do it or someone else. . . . I think it's a huge problem.

## Conclusions and Recommendations:

Participants felt frustrated with the lack of knowledge on trans issues and realities, and a general frustration with service providers who aren't prepared to admit that they don't know. The Trans Needs Assessment was an encouraging first step for many participants. Since the beginning of data collection, ACT has already undertaken several short-term changes based on the findings of data analysis. Participants encouraged ACT to continue efforts at all levels of the agency. Participants divulged very intimate, at times traumatic, experiences with the understanding that their efforts would result in improvements in education, service, and programming concerning health promotion and HIV/AIDS for all trans people. ACT has the potential to take a leadership role in rising to meet the needs of a community that has been marginalized — a community whose needs are not currently being met.

## Recommendations

### Structural

1. **ACT should make an agency-wide commitment to addressing the needs of trans people.**
2. **ACT should create, maintain, and update, as needed, both human resource and program and service policies and procedures concerning trans people, including position statements on transphobia.**
3. **Gather statistics that reflect the diverse trans populations in the city.**
4. **Provide training for staff, volunteers, and clients on trans issues, experiences, and HIV/AIDS and trans people. Training should be offered at regular intervals throughout the year, and should be offered as part of the Volunteer Core Training at the agency.**

### Environmental

1. **Increase the amount of visual imagery and representation of trans people at ACT (posters, signage, pictures, etc.) in publications and on the ACT website.**
2. **Provide at least one gender-neutral bathroom at the agency.**

### Programmatic

1. **In partnership with trans and other AIDS organizations, identify and/or develop HIV prevention messages and materials aimed at trans-bodied people; promote clearer messages about what HIV prevention looks like for trans people.**
2. **Increase the awareness of ACT in trans communities, and HIV/AIDS in trans communities through partnering and networking with trans agencies and individuals.**

3. **Adapt, based on a needs assessment, gender-segregated programming to provide access to gender neutral, gender free, or transgendered people, and for all people for whom gender segregated programming is neither relevant nor appropriate.**
4. **Identify and/or create harm reduction information and materials for trans people who use drugs, and who use needles for hormone injections, etc.**
5. **Initiate, in consultation with other HIV/AIDS and trans service providers, trans-specific HIV/AIDS support programs (in consultations with trans people with HIV/AIDS). This might include support groups, retreats, etc.**
6. **Continue evaluation of referrals lists and materials for relevance to trans communities.**
7. **Develop a way of coding doctors based on their knowledge of trans issues and the presence of trans policies and procedures in their practice/office.**
8. **Create and maintain gender-neutral, safer-sex packages complete with dental dams, gloves, condoms, lube, and assorted safer sex materials, information sheets, and pamphlets.**

### **Community Advocacy and Development**

1. **Maintain and increase partnerships with local agencies, community advocates and individuals in trans communities.**
2. **Advocate for, and/or initiate, research related to trans people and HIV/AIDS including: HIV prevention needs, issues facing trans people living with HIV/AIDS, research on interactions of HIV medications on trans bodies, and research on HIV medication interactions with hormone treatments and SRS.**
3. **Advocate for research into the HIV/AIDS-related needs of Intersexed communities.**
4. **Advocate for the development and expansion of resources on trans histories and experiences; specifically on HIV/AIDS and trans people, trans people of colour, and general health promotion for trans people.**
5. **Provide HIV/AIDS education and support to doctors serving the trans communities (specifically doctors doing SRS, providing hormones).**
6. **Continue to develop a bathhouse education project aimed at increasing access and advocacy.**
7. **Support efforts to increase and improve trans people's access to Toronto's shelter and hostels, in partnership with other agencies.**
8. **Assist with the reproduction and distribution of 'The Happy Transsexual Hooker' booklet, originally developed by the 519 Community Centre but now out of print.**
9. **Advocate for the inclusion of trans data in statistical records on a local, provincial, and national level.**

## **Resources**

1. Feinberg, Les. Transgendered Warriors: Making History from Joan of Arc to RuPaul. Beacon US, 1997
2. Namaste, Vivianne. Invisible Lives: The Erasure of Transsexual and Transgendered People. University of Chicago Press, Chicago
3. Namaste, Vivianne, "HIV/AIDS and Female to Male Transsexuals and Transvestites: Results from a Needs Assessment in Quebec"  
[http://www.symposion.com/ijt/hiv\\_risk/namaste.htm](http://www.symposion.com/ijt/hiv_risk/namaste.htm), 1999
4. Transegender HIV Prevention , Minesota, USA, 2004

## **Appendices**

- a. Request for Proposals**
- b. Outreach Flyer**
- c. Demographics Form**
- d. Consent Form**
- e. Confidentiality Form**
- f. Survey Questions**
- g. Interview/ Focus Group Questions**

## **REQUEST FOR PROPOSALS – Trans Needs Assessment**

The AIDS Committee of Toronto (ACT), in partnership with the Trans Programmes at the 519 Community Centre, is seeking proposals from motivated and experienced consultants to conduct a needs assessment among transgendered and transsexual men and women for ACT education, service and program development.

### **About the Agency:**

**The AIDS Committee of Toronto (ACT) is a community-based, charitable organization that provides support, HIV prevention and education services for people living with and at risk for HIV/AIDS.**

### **About the Project:**

The project resulted from a recent MealTrans presentation at the 519 Community Centre that revealed a gap in consistent trans-specific HIV education, services and programming. With a total project budget of \$8000 (including salary), and working two days per week over a six month period, the successful candidate will carry out two distinct steps:

1. Conduct focus groups with both HIV-negative and HIV-positive transsexual and transgendered men and women to identify HIV risk, HIV education and service needs, and barriers to accessing services.
2. Work with identified ACT staff to develop an action plan, immediate and long term, for the development and provision of focused education and services for trans communities.

### **Desired Experience Includes:**

- ❑ Experience working with the trans communities, specifically with street-involved, sex trade, substance-using, and HIV+ communities.
- ❑ Experience working with community-based grass-roots organizations, and ability to build effective community partnerships.
- ❑ Experience with community-based action research, focus group facilitation report-writing and transcribing.
- ❑ Experience with project management and budget management.
- ❑ Working among diverse communities and cultural competency.
- ❑ Experience working with both trans women and men an asset.

**Responsibilities Include:**

- ❑ Develop work plan and budget.
- ❑ Liaise with and provide regular reports to the Advisory Committee.
- ❑ Plan, coordinate, and conduct focus groups.
- ❑ Transcribe focus group notes and produce needs assessment report.
- ❑ Present report to ACT staff.
- ❑ Work with key staff from each department to develop an action plan.
- ❑ Produce final report on project process and outcomes.
- ❑ Work from ACT office.

**Submissions:**

- ❑ Applicants who are trans-identified are strongly encouraged to apply, as well as people from communities of colour, and people living with HIV/AIDS.
- ❑ Please include examples of similar work as well as list of agencies with which you work or have worked.
- ❑ Please provide a detailed proposed project budget.
- ❑ Please email, fax, mail or drop off your application by 2:00 p.m. on April 16, 2004 to the attention of:

Tania Smith  
Women's Community Development Coordinator  
AIDS Committee of Toronto  
399 Church Street, 4<sup>th</sup> floor  
Toronto ON M5B 2J6  
(Fax) 416-340-8224  
[tsmith@actoronto.org](mailto:tsmith@actoronto.org)

## **Demographic Form – Research Participants**

All information collected on this form will be kept strictly confidential. This data is being collected for the purposes of providing a demographic make-up of this focus group. If you do not feel you can answer a question, please leave it blank or talk to Syrus if you need more information.

### WHO YOU ARE- FOCUS GROUPS Demographics

1. How old are you? \_\_\_\_\_ under 19, 20-29, 30-39, 40-49

2. How would you describe your ethnicity? (for example: person of Colour, Black, East Asian, South East Asian, South Asian, First Nations, Indigenous, Inuit, Latina/Latino, white, or another choice entirely)

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3. How do you identify yourself in terms of your gender identity? (For example: Don't Know, Crossdresser, Transgendered, Transsexual, Shape Shifter, Androgynous, Gender Queer, Tranny, Two-Spirited, or another term entirely...)

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4. Are you a prisoner or ex-prisoner \_\_\_Yes \_\_\_No

5. Are you or have you done some form of sex Work \_\_\_Yes\_\_\_No

6. How would you describe your financial situation (For example: Underwaged, Working, Not Working, or another choice entirely...)

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## Demographics

Age            \_\_\_ 1 \_\_\_ under 19  
                 \_\_\_ 4 \_\_\_ 20-29  
                 \_\_\_ 8 \_\_\_ 30-39  
                 \_\_\_ 3 \_\_\_ 40-49  
                 \_\_\_ 5 \_\_\_ 50-59

## Ethnicity

\_\_\_ 8 \_\_\_ White  
\_\_\_ 4 \_\_\_ First Nations  
\_\_\_ 4 \_\_\_ Mixed Race  
\_\_\_ 2 \_\_\_ Black  
\_\_\_ 2 \_\_\_ South Asian  
\_\_\_ 2 \_\_\_ Latina/o  
\_\_\_ 2 \_\_\_ Jewish  
\_\_\_ 2 \_\_\_ Eastern European  
\_\_\_ 1 \_\_\_ Human

## Gender I.D

\_\_\_ 5 \_\_\_ Transgendered  
\_\_\_ 4 \_\_\_ Transsexual  
\_\_\_ 3 \_\_\_ 2-Spirited  
\_\_\_ 2 \_\_\_ Tranny  
\_\_\_ 2 \_\_\_ Trans Woman/Trans Man  
\_\_\_ 2 \_\_\_ GenderQueer  
\_\_\_ 2 \_\_\_ FemmeBoy  
\_\_\_ 1 \_\_\_ MTF/FTM  
\_\_\_ 1 \_\_\_ Woman/Man  
\_\_\_ 1 \_\_\_ Trans  
\_\_\_ 1 \_\_\_ Gender Free  
\_\_\_ 1 \_\_\_ Gender Dysphoric  
\_\_\_ 1 \_\_\_ Butch  
\_\_\_ 1 \_\_\_ Don't Know

Ex/Prisoner   \_\_\_ 6 \_\_\_ Yes  
                 \_\_\_ 15 \_\_\_ No

Sex Work      \_\_\_ 9 \_\_\_ Yes  
                 \_\_\_ 12 \_\_\_ No

## Economic Situation

\_\_\_ 7 \_\_\_ Working  
\_\_\_ 5 \_\_\_ ODSP/Social Assistance  
\_\_\_ 3 \_\_\_ Underwaged  
\_\_\_ 2 \_\_\_ Not working  
\_\_\_ 2 \_\_\_ Escort  
\_\_\_ 1 \_\_\_ Self-Employed  
\_\_\_ 1 \_\_\_ Student

**CONSENT FORM**  
**Title: Trans Needs Assessment**

**Contact Information:**

Syrus Ware  
The AIDS Committee of Toronto (ACT)  
399 Church Street  
(416) 340.8484 ext 233  
sware@actoronto.org

**Introduction**

We invite you to take part in an assessment being conducted by the AIDS Committee of Toronto (ACT). Taking part in this assessment is strictly voluntary. Participation in this assessment takes one of two (2) formats: participating in a one-on-one interview, or coming to one of three (3) focus groups. Participating in the assessment might not benefit you directly, but we might learn new things that will benefit others. **You may not be HIV+ but by taking part in this assessment, it is possible that some people might think you are.** You should discuss any questions you have about this study with Syrus Ware.

**Who can participate in the Assessment?**

You may participate in this study if you identify as Trans in some way and are living/working/existing in Toronto. Both HIV-positive and negative trans people are eligible to participate in this study.

**Who will be conducting this Assessment?**

This study is being conducted by Syrus Ware from ACT.

**Compensation**

You will be compensated \$20 for your participation in one of the three (3) focus groups. There are ten (10) spaces available in each focus group. You may choose to participate instead by doing one (1) of ten (10) one-on-one interviews with Syrus Ware. You will be compensated \$10 for your participation in a one-on-one interview.

**Confidentially**

Any information you provide will remain strictly confidential and you will not have to give your full name or any other information. The interviews and focus groups will be taped on mini disc. An identification number will be put on your minidisk to link it to your transcribed interview. The list of identification numbers will be kept separate from the original audiotapes and the transcripts. Any information stored on a computer will be in a locked, secure office at ACT.

**Participation**

Your participation in this study is voluntary. You can choose to stop your participation at anytime without negative consequences. You may also refuse to answer any question at anytime.

**Questions or Problems**

If you have any questions regarding your participation in this study now or in the future, you can contact Syrus Ware at ACT 416.340.8484 ext. 233.

**To Obtain a Copy of the Report**

If you would like to obtain a copy of the final summary report, please leave your contact information with Syrus Ware.

Consent for Participation in the Trans Needs Assessment:

I have read and understood the consent form for this Assessment. I have had the Assessment explained to me and I understand any technical language. I understand that the interview will be audio taped and that I will be identified only by an identification number on all documents related to this study. I have had enough time to consider the above information and have had the opportunity to ask questions, which have been answered to my satisfaction. I understand that my participation is voluntary and that I can refuse to answer any questions or withdraw my participation at any time without penalty.

I am voluntarily signing this consent form and understand that I will receive a copy of this consent form for me to keep. If I have any concerns about this study, either now or later about this research, I will contact:

Syrus Ware at (416) 340.8484 ext.233

\_\_\_\_\_  
Participant's signature

\_\_\_\_\_  
Date

I hereby give the researcher permission to audiotape my interview for data interpretation.

\_\_\_\_\_  
Participant's signature

\_\_\_\_\_  
Date

\_\_\_\_\_  
ACT Representative

\_\_\_\_\_  
Date

I have received my \$20 payment for my participation in this workshop.

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Date

The AIDS Committee of Toronto

**Trans Needs Assessment Focus Group**

CONFIDENTIALITY CONTRACT

In this focus group, certain information may be shared which is highly personal and hence not to be known outside the focus group.

All people in this focus group need to understand and therefore agree that personal information is confidential and is not to be shared with people/organizations outside of the focus group.

I, the undersigned, agree to, understand and accept the above principles and will keep confidentiality and personal information shared with me as a result of this focus group.

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(name- please print)

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(signature)

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(witness)

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**(date)**

## **ACT TRANS NEEDS ASSESSMENT**

### SURVEY QUESTIONS

Hello! Thank you for picking up this survey! The data collected in this survey will help ACT develop an action plan for better addressing the needs of the Trans communities in Toronto, and will help ACT assess what the needs and risks are concerning HIV/AIDS in our communities. Thank you for taking the time to fill out this confidential survey. If you would like more information or would like to participate in one of ten one-on-one interviews, please contact Syrus Ware at 416.340.8484 xt.233 or email [sware@actoronto.org](mailto:sware@actoronto.org)

### WHO YOU ARE

1. How old are you?  under 19  20-29  30-39  40-49  50-59  60-69  70-79  80-89

2. How would you describe your ethnicity? (For example: person of colour, Black, East Asian, South East Asian, South Asian, First Nations, Indigenous, Inuit, Latina/Latino, White, or another choice entirely)

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3. How do you identify yourself in terms of your gender identity? (For example: Don't Know, Crossdresser, Transgendered, Transsexual, Shape Shifter, Androgynous, Gender Queer, Tranny, Two-Spirited, or another term entirely...)

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4. Are you a prisoner or ex-prisoner  Yes  No.

5. Are you or have you done some form of sex Work  Yes  No.

6. How would you describe your financial situation (For example: Underwaged, Working, Not Working, or another choice entirely...)

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The goal of this part of the survey is to find out our experiences and thoughts about ACT's current programs and services, facilities, and resources. If you are unfamiliar with ACT, you may still have some helpful suggestions about how ACT could outreach/provide services to you.

ACT ASSESMENT

1. a) Have you accessed any of ACTS services or programs?  
\_\_\_\_\_yes\_\_\_\_\_no

b) If so, what was the program/service

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c) How would you describe your overall experience with this program/service? Were you satisfied?

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d) Would you use ACT's services again in the future? Why/why not?

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2. Why haven't you used ACT services?

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3. Are you satisfied with the location and hours of operation of ACTS services?

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4. Are you satisfied with the options you have for services as a trans person in Toronto? Why or why not?

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5. What do you like about ACT?

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6. In your opinion, what have been the challenges with ACT and ACT's attempts to serve people in the Trans communities?

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7. What can ACT do to recruit participation of trans people in its programs and services?

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8. What would it take to make ACT a place where trans people feel ownership? What would make it possible for you to become involved in using ACT's programs, services, and information campaigns? \_\_\_\_\_

The goal of this next part of the survey is to find out what we know or don't know about HIV/AIDS, where we go to get info on HIV/AIDS, and to find out what HIV/AIDS services/programs are needed for trans people in Toronto.

#### HIV/AIDS NEEDS ASSESSMENT

1. Where do you get information on HIV/AIDS?  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_
2. In your opinion, what are the behaviors are unique to the trans communities that would increase our risk of HIV transmission?  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_
3. What else impacts the prevalence or rates of HIV in trans communities? \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_
4. What is the most important HIV-related service/care you are using now or have used in the last year?  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_
5. Where are you going to get info /services to meet your needs?  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_
6. What services or care do you need, but are unable to get?  
\_\_\_\_\_

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7. While seeking services/information on HIV/AIDS, have you experienced any problems?

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8. What would be the single most important change you would suggest to improve services to trans people living with HIV/trans people seeking HIV prevention materials and info?

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9. If there was one thing you could change about services for trans people living with HIV, or one recommendation you could make to providers or those trans communities — what would it be?

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10. Is there anything else you would like to add?

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## **Focus Group and Interview Questions**

### ACT TRANS NEEDS ASSESSMENT

#### ACT ASSESMENT

1. Who/what is ACT?
2. What do we know/think about ACT's current programs and services?
3. Are you satisfied with the location and hours of operation of ACT's services?
4. Have you accessed any of ACTS services or programs?
5. Are you satisfied with the particular services you have used? (Prompt: medical care, case management, transportation, mental health, substance abuse counseling, support groups, etc.) Why/why not?
6. Are you satisfied with the options you have for services? (E.g. the providers/agencies available.) Why or why not?
7. What do we like about ACT?
8. What have been the challenges with ACT and their attempts to serve people in the Trans communities?
9. How can ACT's programs and services be more accessible to trans people?
10. What would it take to make ACT a place where trans people feel ownership? What would make it possible for you to become involved in using ACTS programs, services, and information campaigns?

#### HIV/AIDS NEEDS ASSESSMENT

11. Where do we get information on HIV/AIDS?
12. How prevalent do we feel HIV/AIDS is in the Trans communities?
13. What behaviors are unique to the Trans communities?
14. What else impacts the prevalence of HIV in Trans communities?
15. What are the most important HIV-related services/care you are using now or have used in the last year? (Prompt: medical care, condoms/dental dams distribution, mental health related services, support groups, etc.)

16. Where are we going to get info /services to meet our needs? (Friends, other AIDS service providers, community-based organizations providing social services, neighborhood clinics, hospitals, etc.)
17. What services or care do trans people need, but are unable to get? (Housing, food, respectful health care, access to prescription drugs/medication, HIV/AIDS info targeted to trans people, benefits?)
18. While seeking services/information on HIV/AIDS, have you experienced any problems? (Unhelpful attitudes, behaviors, travel a great distance to receive service, transportation problems, inconvenient hours of operation, having to pay a fee for services, unmanageable waiting time to get an appointment or to see a provider once you are there, hassle by staff or other clients, child care, language/cultural barriers)
19. What would be the single most important change you would suggest to improve services to Trans people living with HIV/Trans people seeking HIV prevention materials and info?
20. If there was one thing you could change about services for trans people living with HIV, or one recommendation you could make to providers or those trans communities — what would it be
21. Is there anything else you would like to add? Are there any questions that I can answer before we end the session?