

**studio
180**

The Normal Heart

Study Guide

2012/13

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A. Notes for Teachers

Thank you for bringing your students to see *The Normal Heart*, produced by Studio 180 Theatre in association with Buddies in Bad Times Theatre. This Study Guide is intended to help make your class's experience as enjoyable and as memorable as possible.

Larry Kramer's *The Normal Heart* chronicles the early years of the AIDS epidemic in New York City, addressing issues of homophobia, discrimination, sexuality, health, community, justice and political activism. Studio 180's productions often tackle such potentially sensitive topics and we have developed the following guidelines to help you lead productive pre- and post-show sessions in which all students feel safe, respected and able to contribute openly and honestly to discussion.

- Class members should agree on a set of ground rules that will steer the discussion. Ask for student input on what those principles should be. Examples of ground rules might include a commitment to confidentiality within the classroom and to respecting others, a ban on the use of slurs and an agreement that only one person will speak at a time.
- Your class may include students from a wide variety of cultural, racial, religious and national backgrounds. Most likely your class includes openly Lesbian, Gay, Bisexual, Transgender or Queer ("LGBTQ")-identified students, LGBTQ students that have not come out and/or students who are questioning or experimenting with gender and sexuality. Teachers and students must resist the urge to place individuals in the spotlight based on their perceived identity or point of view. Students will enter into the conversation as they feel comfortable.
- It is the moderator's role to establish as safe a setting as possible and must take special care to ensure that students holding a majority opinion do not vilify those "on the other side" who hold a minority view. The moderator should also pose questions to the class to help keep the conversation on track.
- The point of a classroom discussion about the issues addressed in *The Normal Heart* should not be to reach a class consensus. The goal should be to establish a forum for a free and respectful exchange of ideas.
- Please keep in mind that the better students are prepared prior to attending the play, the more they will get out of the experience. An awareness of what they are about to see will provide students with greater access to the ideas presented onstage. For this reason, this Study Guide is filled with background information and suggestions for classroom discussions and activities. Upon request, we can also offer a free pre-show chat beginning 45 minutes prior to each Wednesday matinee.

Your students' experiences of the play will also be heightened by effective follow-up class discussion. We offer post-show Q&A sessions after every Thursday matinee to assist in the follow-up process, but it is important to note that students will continue to process their experiences long after they leave the theatre. If time permits, a follow-up discussion a few days later will likely be helpful and productive.

If you are interested in finding out about Studio 180's production-based workshops, please contact **Jessica** at **416-962-1800** or jessica@studio180theatre.com.

C. Introduction to the Company and the Play

Studio 180 Theatre

Inspired by the belief that people can engage more fully in the world through the experience of live performance, Studio 180 produces socially relevant theatre that provokes public discourse and promotes community engagement. Our inaugural production of *The Laramie Project* played to sold-out houses at Artword Theatre in 2003. Its success led to a 2004 remount at Buddies in Bad Times Theatre, earning two Dora Award nominations and selling out public and student performances. We were deeply affected by the response to *Laramie*, which revealed to us the potential of theatre to transform.

Since then, Studio 180 has continued to offer acclaimed productions of plays that tackle difficult issues and generate powerful audience and community responses. These are often Toronto, Canadian and/or North American premieres of large ensemble pieces that are contemporary, internationally renowned, and unlikely to be produced elsewhere –

- In 2006, we presented the Canadian premiere of British playwright Robin Soans' *The Arab-Israeli Cookbook* at the Berkeley Street Theatre Upstairs.
- In March 2008, the Canadian premiere of *Stuff Happens* by British playwright David Hare ran at the Berkeley Street Theatre Downstairs.
- In October 2008, we presented the world premiere of *Offensive Shadows*, by Toronto playwright Paul Dunn, at the Tarragon Theatre Extra Space. The *National Post* named it one of the best new Canadian plays of the year, and *NOW Magazine* named Studio 180 "Toronto's Best Independent Theatre Company of 2008."
- In October 2009, we produced a one-night-only benefit performance of *The Laramie Project: 10 Years Later*, Tectonic Theater Project's epilogue to the original play.
- In November 2009, Mirvish Productions remounted our acclaimed production of *Stuff Happens* at Toronto's historic Royal Alexandra Theatre.
- For our 2008/09 through 2011/12 seasons, Studio 180 participated in the Berkeley Street Project Initiative, producing one show annually (in March/April) as part of the Canadian Stage subscriber season. Productions included the Canadian premieres of *Blackbird* by David Harrower (2009) and *The Overwhelming* by J.T. Rogers (2010), the North American premiere of *Our Class* by Tadeusz Slobodzianek (2011) and the Canadian premiere of Pulitzer Prize-winning *Clybourne Park* by Bruce Norris (2012). Two Dora nominations.
- In December 2010/January 2011, we co-produced the Tony Award-winning musical *Parade* with Acting Up Stage Company. Two Dora nominations, including Outstanding Production of a Musical.
- In October 2011, we produced Larry Kramer's landmark drama *The Normal Heart* in association with Buddies in Bad Times Theatre (one Dora nomination). We are pleased to be partnering with Buddies in Bad Times once again to bring this production back in October 2012.

Studio 180 is also dedicated to fostering Canadian voices by supporting local playwrights. We are currently working with award-winning playwright Hannah Moscovitch (*The Children's Republic, East of Berlin, In This World, The Russian Play, Essay*) on a play inspired by the tragic murder of Mississauga teenager Aqsa Parvez.

The Normal Heart

In the early 1980s a deadly epidemic was decimating North America's gay population, killing people in the thousands, devastating an entire generation and changing the way we think about sex forever. Playwright and activist Larry Kramer's landmark drama about the early years of AIDS in New York City puts a human face to an issue often mired in numbers, facts and statistics.

New York City. 1985. Openly gay writer Ned Weeks watches in horror as friends and lovers fall prey to a mysterious virus targeting his community. *The Normal Heart* is a call to arms, chronicling Ned's personal crusade for justice amidst resistance, intolerance and ignorance on the part of governments, family and friends.

A fierce indictment of a world unwilling to confront the AIDS epidemic, *The Normal Heart* polarized the gay community when it was first performed at New York's Public Theatre in 1985 – where it earned a Dramatists Guild Marton Award, the City Lights Award, the Sarah Siddons Award for the best play of the year, and a nomination for an Olivier Award – and it has never been produced at Toronto's Buddies in Bad Times Theatre until now. Playwright Larry Kramer's controversial endorsement of abstinence combined with his highly politicized and combative spirit have made him a hero to some and a threat to others. Amidst controversy, however, *The Normal Heart* has endured, and today this document of recent history is as relevant and powerful as it ever was – a reminder that battles for justice, equality and dignity are not just things of the past.

In 2011 *The Normal Heart* received its Broadway debut, earning rave reviews and a number of prestigious awards: Tony Awards for Best Revival of a Play, Best Featured Actress (Ellen Barkin) and Best Featured Actor (John Benjamin Hickey); Drama Desk Awards for Outstanding Revival of a Play, Outstanding Director of a Play and Outstanding Ensemble; the Outer Critics Circle Award for Best Revival of a Play; and a New York Drama Critics Circle Special Citation.

Studio 180 proudly partnered with Buddies in Bad Times Theatre to share this powerful and important play with Toronto audiences in the fall of 2012, earning a Dora Award nomination (Ryan Kelly for Best Performance in a Featured Role) and being lauded as one of the top productions of the year by Toronto's major theatre critics. We are pleased to have the opportunity to reach even more Torontonians with our October/November 2012 remount at Buddies in Bad Times Theatre.

WARNING: Very strong language and challenging subject matter, including frank discussions of sexuality.

Examples of the strongest language used in the play include the words FUCK, FUCKING, COCK and FAGGOT. All such language is spoken within the context of political arguments, and not in a sexually explicit context. For example, one character asks, "If having sex can kill you, doesn't anybody with half a brain stop fucking?" Another example: "I am sick of guys who can only think with their cocks." Again, these excerpts represent the strongest language spoken in the play.

The production contains NO nudity and, while sex and sexuality are discussed, sex is neither acted out nor physically represented.

If you have questions or concerns about the content of the play please do not hesitate to contact **Jessica** at jessica@studio180theatre.com or **416-962-1800**.

Larry Kramer – Playwright

Controversial playwright, novelist and essayist Larry Kramer has been a pioneer in the gay political response to AIDS in America.

Kramer was born into a well-to-do professional family in Bridgeport, Connecticut, in 1935. He completed a B.A. at Yale in 1957 and served in the army for a year after graduating. In 1958, he began a career in the entertainment industry, working first for the William Morris Agency and then for Columbia Pictures. His first professional writing was the screenplay for the 1969 movie adaptation of D.H. Lawrence's *Women in Love*, which he also produced and for which he received an Academy Award nomination.

Kramer gained prominence in the world of gay writing in 1978 when his novel *Faggots* was published. A scathing satire of the gay circuit in Manhattan and on Fire Island, the novel traces the life and neuroses of Fred Lemish, a middle-aged Jewish gay man looking for love in a world that only wants to have sex. The world of fast-lane gay New York becomes the real subject of the book, and Kramer's narrative focuses on the drug and alcohol abuse, the sado-masochism and the promiscuity that he sees as both typical and reprehensible.

The novel met with immediate hostility from reviewers in both the gay and straight press, yet ironically went on to become a best-seller. In 1987, when the novel was reissued, politics and disease had forced many changes in the community Kramer lampooned, and both gay and straight readers were considerably more laudatory of the book.

Although *Faggots* marked an important breakthrough novel for gay publishing, Kramer himself will most likely be remembered as an AIDS activist. In 1981, he co-founded Gay Men's Health Crisis in New York, the first community-based AIDS service organization in America. Disenchanted with what he perceived to be the lethal dangers of an uncontrollable AIDS bureaucracy, he founded AIDS Coalition to Unleash Power ("ACT UP") in 1988, which became and remains one of the most powerful direct action political groups in America.

Spurred on by his own HIV-positive status and his work in the AIDS field, Kramer wrote *The Normal Heart* in 1986, one of the first artistic responses to the AIDS crisis. The play, which established Kramer as a dramatist, received the Dramatists Guild Marton Award, the City Lights Award, the Sarah Siddons Award for the best play of the year, and a nomination for an Olivier Award.

The Normal Heart tells the story of Ned Weeks, an AIDS activist who defies the AIDS service establishment and preaches for an extreme response to AIDS, including sexual abstinence. Like *Faggots*, *The Normal Heart* polarized the gay community, but unlike *Faggots* it has been universally received as a major work of art.

Kramer's most recent writings have been direct political polemics, all of which have been gathered in *Reports from the Holocaust: The Making of an AIDS Activist* (1989). He continues to produce theatrical pieces, such as *The Destiny of Me* (1992), which extends the story of Ned Weeks, and some short fiction; however, at this point there is little doubt that he will be best remembered as the man who almost single-handedly began the gay political response to AIDS in America.

D. Attending the Performance

Prior to the performance, please ensure that your students are well prepared. The better prepared they are, the more they will get out of the experience. The following guidelines should help you and your students get the most out of attending *The Normal Heart*:

- **Please arrive early.** When travelling in the city, whether by school bus or TTC, it is always best to leave extra time in case of traffic or transit delays. All Thursday matinee performances will begin promptly at **1:00PM**. To avoid disruption, **LATECOMERS** will be seated at the discretion of the front of house staff, during an appropriate break in the action.
- Depending upon where you are coming from, your students may not be familiar with downtown Toronto and the experience of being in the city may be exciting and even overwhelming or distracting for some. We ask that you kindly advise your students to remain at the theatre during intermission. If possible, you may want to consider allowing time prior to the performance for students to explore the area. Buddies in Bad Times Theatre is located just east of bustling Yonge Street where stores and restaurants abound. One block east of the theatre is Church Street – Toronto’s hub of LGBTQ culture and community life. If time permits, we highly recommend you include a visit to the **AIDS Memorial** located in Cawthra Square – just north of Wellesley Street East and east of Church Street (See **Section I** of this Study Guide).
- Food and beverages are not permitted in the auditorium and **all photography and recording of the performance is strictly prohibited**. Please impress upon your students the importance of turning off all cell phones, iPods and other electronic devices. **Remind students that they will be seeing people performing live** and, as a rule, if you can see and hear the actors, the actors can see and hear you. Even text messaging – with its distracting, glowing blue light – is **extremely disruptive** in the theatre. **Please be courteous.**
- **CONTENT WARNING:** *The Normal Heart* contains some very strong language and challenging subject matter, including discussions of sexuality. If you have concerns about content or language prior to attending the performance and wish to receive further details, please do not hesitate to contact **Jessica** at jessica@studio180theatre.com or **416-962-1800**.
- We encourage student responses and feedback. Please take the time to discuss appropriate audience responses with your students. After each Wednesday matinee and Thursday evening performance, we offer a talkback (Q&A) session because we are interested in hearing what our audiences have to say, and we hope to answer questions and respond to concerns. It may be helpful for students to think of some questions prior to attending the performance. As well, if students are aware of the post-show talkback they will be better prepared to formulate questions during the performance. We are also happy to offer pre-show chats for student groups upon request. Please inquire at the time of booking. Following the performance, kindly take a moment to complete **Section B. Teacher Response Form**. Your feedback is valuable to us.

E. Background Information

1. Homophobia and Heterosexism

“Anti-homophobia education is no different from education to combat harassment and discrimination related to race, religion, gender, disability, or class. People will only be treated with respect if the biases, stereotypes, prejudices, myths, and negative ideas about them are dispelled.” – *Challenging Homophobia and Heterosexism: A K-12 Curriculum Resource Guide*, Toronto District School Board, 2011.

The Normal Heart is about AIDS. It is also very much about the gay community. There was a time in North America where the two were nearly synonymous – this is the world of the play. Over the years, however, the face of HIV and AIDS has shifted significantly and what was once labelled a “gay disease” is something we now know can affect all of us regardless of sexual orientation, race, class, gender or nationality. Today, on a global scale, the majority of people living with HIV and AIDS (“PHAs”) are heterosexual – including women and children.

Herein lies a significant and complicated tension regarding teaching about HIV/AIDS.

It is crucial that students understand that AIDS is not a “gay disease.” People who identify as members of the Lesbian, Gay, Bisexual, Transgender or Queer (“LGBTQ”) community are not predisposed to contracting the virus. In fact, years of associating AIDS with the gay community has deepened homophobic thinking and perpetuated harmful stereotypes and stigmatization, all the while allowing society to ignorantly label the epidemic as a “gay problem” – something that the gay community should take care of by “looking after their own.”

At the same time, 30 years after the first reported AIDS cases in North America, knowing the history of the epidemic remains vital to understanding the ways in which the disease has been and continues to be severely stigmatized. We must recognize the major contributions to AIDS awareness and activism made by members of the gay community. The leaders and foot soldiers who pioneered the AIDS activist movement were predominantly gay men and, drawing on the experiences of women’s health activists, their efforts revolutionized the ways in which governments and the medical industry address health care. *The Normal Heart* honours this history and acknowledges the roots of the political and human rights struggles of gay activists and PHAs.

We hope that by seeing *The Normal Heart* and taking the time to discuss the play, students will gain an awareness of the history of HIV/AIDS and how it is connected to LGBTQ rights and to the struggle to combat homophobia. We hope students will take the time to learn the facts about HIV/AIDS so that they are armed to protect themselves against infection. HIV is preventable and the greatest defence we have against it is education. We hope this theatrical experience, together with resources provided in this Study Guide, will inspire students to think, talk and learn more about issues around HIV/AIDS so that they may develop empathy and compassion, and maybe even get involved at the community service or advocacy levels.

Class leaders without prior experience teaching anti-homophobia and heterosexism should refer to published school board guidelines. We recommend the TDSB’s 2011 Equitable and Inclusive Schools’ *Challenging Homophobia and Heterosexism*

Resource Guide for Kindergarten to Grade 12 Curriculum. You can [download the complete PDF](#) from the TDSB website.

All discussions surrounding *The Normal Heart* should begin with the class leader's assessment of what students already know and understand. When conducting in-class workshops we like to begin with group brainstorming sessions around key themes and terminology. For some groups, the following definitions provided by the *Challenging Homophobia and Heterosexism* Resource Guide may be useful:

Bias

Bias is the opinion, preference, inclination, perspective or slant that informs actions and/or text. Bias can be positive or negative. This definition differs from a common usage in which bias has only negative connotations, such as prejudice, unreasoned justification, distorted interpretation and unfair influence. To deal with text knowledgeably, the reader must interpret it from competing perspectives, and determine whether bias is positive or negative.

Stereotypes

A stereotype is a false or generalized conception of a group of people, which results in the unconscious or conscious categorization of each member of that group without regard for individual differences. Stereotyping may be based on misconceptions and false generalizations about racial, age, ethnic, linguistic, religious, geographical or national groups; social, marital or family status; disability, gender or sexual orientation. Stereotypes are often developed with little thought and they can lead to high levels of resentment. Stereotypes lead to inequities of all kinds: employment, housing, social acceptance and all forms of exclusion.

Prejudice

Prejudice is a set of opinions about or attitudes toward a certain group, or individuals within it, that casts that group and its members in an inferior light, and for which there is no legitimate basis in fact. It can be a consequence and a cause of discrimination. The term is derived from the word "prejudge." Prejudicial attitudes are very resistant to change because concrete evidence that contradicts the prejudiced view tends to be dismissed as "the exception to the rule."

Discrimination

Discrimination is the differential allocation of goods, resources and services, and the limitation of access to full participation in society, based on individual membership in a particular social group.

Homophobia

Homophobia refers to the social, systemic and personal assumptions, practices and behaviours that impose negative value on and discriminate against homosexual women and men. Homophobic acts can range from name-calling, to violence targeting lesbian or gay people, to eliminating them from curriculum, or to not providing legal and social supports.

As an introductory exercise, write the following on the board and ask students to complete the sentence: "I know homophobia is happening when I see/hear..."

The TDSB's 2011 Equitable and Inclusive Schools' *Challenging Homophobia and Heterosexism* Resource Guide for Kindergarten to Grade 12 Curriculum offers numerous activities for engaging in classroom anti-homophobia and heterosexism work. The following is one example we recommend:

Activity 2: Aspects of Identity and Contextual Power

James Banks Continuum: Stage 1

Time: 75 minutes

Description

The overall goal of this activity is for students to realize that no one has “all the power” or “none of the power” and that power changes based on context. During this activity students will reflect on the different aspects of our identity. Students should begin to recognize and consider the idea that we may not choose parts of our identity and there are other parts of our identity that we might change. Students are also introduced to some basic anti-oppression terms. Finally, through real-world examples, students will recognize that power is relative to particular situations: what gives you power in one situation might work against you in another.

In relation to Anti-Homophobia education, this activity provides multiple opportunities for a facilitated discussion on whether being LGBTQ is a choice and how the choice to “come out” can help or hurt you in different situations.

Planning Notes

- Teacher prints and cuts out each individual “Aspect of Identity.” You will need as many envelopes as you have groups. Seven to twelve aspects should be placed in an envelope: when grouping your aspects, you should try to avoid stereotyping. See Appendix 2.1 for examples of aspects and groupings.
- Prepare your working definitions for privilege, oppression, equity and equality. You may choose to have something ready on chart paper but do not display it until after the first phase of the activity. For definitions on some of these terms, you can refer to the TDSB document, *A Teaching Resource for Dealing With Controversial and Sensitive Issues in Toronto District School Board Classrooms*, specifically p. 67: www.tdsb.on.ca/wwwdocuments/program+s/Equity_in_Education/docs/CSI_2003.pdf
- Prepare and print out your list of contexts. See Appendix 2.2 for examples.
- Prepare discussion questions or journal prompts. See Appendix 2.3 for examples.

Prior Knowledge

None

Continued

Teaching/Learning Strategies

Part A: Aspects of Identity (35 minutes)

1. Place students into random groups: do not let them choose their group members. Groups of 5–6 work best but it can also be done with groups of up to 15 members.
2. Explain to the students that they are about to be given an envelope that represents a Grade 9 student. Inside each envelope will be different aspects (traits, characteristics, past experiences) of this pretend person's identity. If you are comfortable with the analogy of identity as a "backpack," you may choose to use that now. Do not explain the concepts of privilege or oppression yet.
3. Give each group an envelope with the 7–12 "Aspects of Identity" that you have already prepared. Make sure that each aspect is on a separate piece of paper because students will be physically shuffling them around.
4. Ask the students to quickly physically sort each of their "Aspects of Identity" into one of two categories based on whether they are things you can't choose (fixed, can't be changed, e.g. they were born) or something that you can choose (can be changed, was learned, e.g. thoughts). Essentially, does the imaginary student have the power to change this aspect of their identity or not? Note: it is not important that the students complete the task or agree on their choices – the real goal is to have students in groups discussing and debating what aspects of identity you do or don't have power over.
5. Each group briefly gives a report-back, just naming each aspect of identity and which of the two categories they put the trait in. At this point, you might feel the need to facilitate a debrief discussion on some of the group choices.

Part B: Working Definitions (10 minutes)

1. Provide students with working definitions for the following terms: oppression, privilege, equity and equality.

Part C: Privilege and Oppression as Contextual (30 minutes)

1. Explain to students that these "Aspects of Identity" can be both positive and negative. An aspect that is positive in one situation might be negative in another. This means that context (space and place) changes which aspects give you power and privilege.
2. Explain to the students that you are going to shout out different contexts. When you shout out a context, you want them to quickly group all their aspects as being an advantage, disadvantage or neutral.
3. Shout out the different contexts. If you are running behind with your time, you can do this very quickly, like a "speed round."
4. Facilitate discussion on the activity. Refer to Appendix 2.3 for sample discussion questions. Or ask students to reflect on the activity by journaling. Refer to Appendix 2.3 for sample journaling prompts.

Continued

Assessment and Evaluation

- Journaling can be used to assess or evaluate written communication and metacognition skills.
- Teacher can track oral responses from the facilitated discussion to generate both oral communication and thinking/inquiry assessment.

Accommodations/Extensions

- Large print Appendix 2.1: Aspects of Identity are recommended.

Resources – Electronic

- *A Teaching Resource for Dealing With Controversial and Sensitive Issues in Toronto District School Board Classrooms*
www.tdsb.on.ca/wwwdocuments/program+s/Equity_in_Education/docs/CSI_2003.pdf

Appendices

- Appendix 2.1: Aspects of Identity
- Appendix 2.2: Suggested Context List
- Appendix 2.3: Discussion Questions and Journal Prompts

Continued

Appendix 2.1: Aspects of Identity

Possible Student “Identity Packages”

Student 1	<ul style="list-style-type: none">• MALE• NOT SURE IF HE IS STRAIGHT/HETEROSEXUAL• PARENTS ARE DIVORCED AND STILL FIGHT• JEWISH• SHORT• GOOD AT MUSIC BECAUSE THEY PRACTICE ALL THE TIME• SPENDS ABOUT 3 HOURS A DAY BABYSITTING 2 YOUNGER SISTERS• THINKS THEY ARE OVERWEIGHT• IS VERY FUNNY AND WELL-LIKED
Student 2	<ul style="list-style-type: none">• MALE• KOREAN• IS ADOPTED BY 2 PARENTS• CHRISTIAN• CAN'T AFFORD THINGS LIKE FIELD TRIP FEES OR NEW CLOTHES• TALL• SOMETIMES HAS MILD SEIZURES• IS FEELING DEPRESSED LATELY
Student 3	<ul style="list-style-type: none">• MALE• BLACK• IS GREAT AT INDEPENDENT WORK BUT DOESN'T LIKE GROUPS• MOM IS VERY SICK AND HAS BEEN FOR A LONG TIME• DOESN'T GET AN ALLOWANCE• ASTHMATIC• HAS ALWAYS BEEN GOOD AT ART• THINKS THEY ARE UGLY
Student 4	<ul style="list-style-type: none">• FEMALE• WHITE• LESBIAN• ALWAYS BEEN GREAT AT READING AND WRITING• DAD DRINKS TOO MUCH• IS VERY POPULAR IN SCHOOL• WORKS A PART-TIME JOB 4 NIGHTS A WEEK FOR 5 HOURS• IS VERY CONFIDENT AND SECURE
Student 5	<ul style="list-style-type: none">• FEMALE• DYSLEXIC• HAS 2 SUPPORTIVE PARENTS• MUSLIM• RICH• GOOD AT SPORTS• HAS NO CLOSE FRIENDS

Continued

Appendix 2.2: Suggested Contexts List

Being on the basketball team

At a school dance

In math class

Doing a group project for English class

Going to a school overnight retreat

Being on Student Council

Walking alone at 11pm at night

Being randomly stopped by a police officer

Preparing for a major test

Wanting to ask someone out on a date

Working on the school newspaper

Going to parent-teacher interviews

Trying to get a part-time job

Trying to replace a textbook stolen from their locker

Being active on Facebook

Being asked to do an assignment that requires 3 hours on the computer

In the change room after gym class

Needing to find a lab partner when their usual one is absent

Trying to get extra help from a teacher after school

Continued

Appendix 2.3: Discussion Questions and Journal Prompts

The questions below can be used for facilitated discussion or as journal prompts.

- What were some of the aspects of identity that were mostly hidden but that you think probably really affect people?
- Some people think that some aspects of identity are more important than others. Why do you think some people feel this way?
- What are the kinds of aspects of identity that seem to “trump” or beat out all the others? Why might this be?
- How might your imaginary student look different in 10 years? Why do youth have less power to change who they are and their situation than adults?
- Many of the aspects we looked at today would be hidden. Now that you are thinking more about how these hidden aspects might affect a person, how are you going to try and treat people differently?
- What can schools, classrooms or teachers do to make things more equal?
- How can we be more gentle and respectful with each other when school is often a place of competition and social stress?
- If you could go back in time and talk to your Grade 7 self (for high school) or Grade 6 self (for intermediate) about what we talked about today, what would you say?

Anti-Homophobia Focus

- Thinking about all the aspects we talked about today, are there some that would make it harder for a person who is gay or lesbian to “come out”?
- What are the situations where it is most difficult to be gay or lesbian?
- You can’t choose to be gay or straight but you can choose to “come out.” Why do you think some people “come out” when they are 14 and others “come out” when they are 40?

Journal Prompts Only

- What do you think are the three most important aspects of your identity and why?
- Think of an incident when you didn’t think about the tough times another student may have been going through. What would you do differently now?

2. HIV and AIDS: The Basics

Provided by the AIDS Committee of Toronto (“ACT”), January, 2011. Reprinted with permission.

What is AIDS? What is HIV?

AIDS stands for Acquired Immune Deficiency Syndrome. AIDS is caused by a virus known as the Human Immunodeficiency Virus, or HIV.

How does HIV infection lead to AIDS?

HIV attacks the body’s immune system, our defence against infection and disease, and weakens it over time. A person who has HIV gradually loses the protection of his or her immune system and begins to experience health problems. These may be fairly small problems at first – skin problems or yeast infections – but over time the illnesses become more serious. The amount of time that it takes HIV to begin to affect a person’s health varies widely from one individual to another. When a person is diagnosed with one of the serious illnesses or cancers that are “AIDS-defining,” the person is then said to have AIDS.

HIV attacks the immune system mainly by damaging the CD4 (also known as T4 or T-helper) cells that help the body fight off diseases. HIV can also have direct effects upon the body. For example, the virus can attack cells in the brain and impair the brain’s function.

How could I become infected with HIV?

HIV is a fragile virus that cannot survive outside of the body. That is why you cannot be infected with HIV from toilet seats or from sharing dishes or utensils. HIV does not get passed through the air – as a cold or flu does.

HIV-infected body fluids must reach the HIV-susceptible cells in the blood, usually through a break in the skin, absorption through mucosal membranes (mucosa) or through some disruption to the mucosa. Mucosa are the moist surfaces of the body which line most of the body cavities and hollow internal organs such as the vagina, rectum, mouth, urethra, nose and eyelids.

HIV does not get passed from one person to another through deep kissing, mutual masturbation or inserting fingers into the vagina or anus (“ass,” “bum” or “butt”). You cannot get HIV from body fluids such as saliva (spit), sweat or urine (pee).

There are five body fluids that have enough HIV in them to infect someone:

- Blood
- semen (cum)
- vaginal fluids (including menstrual fluids)
- rectal fluids
- breast milk

Sex

The most likely way that enough HIV gets into a person's bloodstream is through the interior skin or linings – the mucous membranes – of the vagina, the cervix (which is inside a woman's vagina), the rectum ("ass," "bum" or "butt"), or the urethra (this is what we pee through – it's the tube inside a man's penis, or in front of the vagina in women). HIV can be transmitted if you have anal or vaginal sex without a condom or if you share sex toys – such as a dildo, vibrator or butt plug – that have not been cleaned each time someone uses them.

Having anal or vaginal sex without a condom, or sharing sex toys without washing them carefully, or not using a new condom between partners are all very risky activities. HIV can get into the bloodstream through the mouth and throat. This is rare. Some people have gotten HIV when they have performed oral sex (given a man a "blow job" or "gone down" on a woman) but it is rare. No one gets HIV from someone going down on them.

When a person has a sexually transmitted infection ("STI") like syphilis, gonorrhea, warts or herpes, his or her risk for getting HIV increases a lot. Regular check-ups are important as one way of preventing HIV transmission.

Most people get infected with HIV when they have anal or vaginal sex without a condom or when they share a needle/syringe/cooker to inject drugs.

Needles

Another common way that HIV is transmitted is through a puncture from a needle that has already been used by someone else and has not been cleaned. When people who are injecting drugs share their "works" (needle, cooker, etc.) it is easy to get HIV. It is also easy to get other infections, such as hepatitis C, from sharing your works.

Pregnancy

HIV can be transmitted from mother to child during pregnancy, labour or delivery. Without anti-HIV drug treatment there is about a 25% chance the child will be infected. With treatment, the rate drops to about 3%. However, the long-term effects of the drugs on the child are not yet known. HIV can also be passed to a child through breastfeeding if the mother has HIV.

Blood transfusions and blood products

In the past, some people were infected with HIV through blood transfusions and blood products used to treat illnesses like hemophilia. However, since 1985 all donated blood in Canada is tested for HIV. You will not become infected when you donate blood.

How do I know if I have HIV?

You can't tell if you have HIV by how you look or feel. You can't tell whether another person has HIV by looking at him or her. People with HIV can look and feel healthy for many years. The only way to know if you have HIV is by having a blood test. This test is known as an "HIV test" or an "HIV antibody test." You may have heard it referred to as an "AIDS test" but the test does not tell you if you have or will get AIDS; it tells you only whether you have been infected with HIV.

This test looks for antibodies that are made by the immune system when a person is infected with HIV. It is a very accurate test. If antibodies to HIV are found, the test result

is referred to as “positive.” The person is HIV antibody positive (or “HIV positive,” or “HIV+”). This means that the person has been infected with HIV.

If antibodies are not found, the test result is referred to as “negative” and the person is HIV antibody negative (or “HIV-negative,” or “HIV-”). This means that the person has not been infected with HIV.

There is a gap between the time a person is infected with HIV and the time when the antibodies are formed. This period can be from 3 to 12 weeks. It is called the “window period.” For this reason, it is important to wait for twelve weeks after engaging in activities that may have caused HIV infection before getting tested. This will ensure an accurate HIV antibody test result.

What happens after someone is infected with HIV?

Soon after infection, some people experience a brief, flu-like “seroconversion illness” at the time when antibodies to HIV are being created. But most feel completely well and have no symptoms. During this period, the person is said to be “asymptomatic.” They may not even know they have been infected. They may continue to feel well for a long time. In fact, some people who were infected with HIV over 10 or 15 years ago continue to feel completely well today.

During the period when the person with HIV is feeling healthy, their CD4 cells are defending the body against HIV. Lab results would likely show that the person’s CD4 count to be fairly high and their viral load (which measures the amount of HIV in the blood) to be fairly low.

Although researchers are working to try to produce treatments that will remove all traces of HIV from an infected person’s body, at this point in time we understand that once a person is infected with HIV, the virus cannot be completely destroyed or eradicated. It continues to reproduce and to attack the immune system. At a certain point, the CD4 cells are overpowered and can no longer keep HIV under control. The person’s CD4 count then declines and their viral load rises.

As their CD4 cells decline, a person with HIV becomes vulnerable to various infections and illnesses. This period of declining health is sometimes referred to as the “symptomatic period.” The organisms that cause these infections are quite common and present in most people’s bodies but are kept under control by a healthy immune system. As HIV weakens the person’s immune system, these organisms can no longer be controlled, and illness occurs. These illnesses are known as “opportunistic infections” and include such diseases as pneumocystis carinii pneumonia (“PCP”) and toxoplasmosis (“toxop”).

Early in the epidemic, the US Centers for Disease Control compiled a list of serious illnesses that result from the weakening of the immune system in people with HIV. Once a person has experienced one or more of the diseases on this list of “AIDS-defining conditions,” he or she is said to have AIDS. A person with AIDS typically has periods of relatively good health in between serious illnesses. People have lived for years with an AIDS diagnosis. There are drugs that can prevent certain AIDS-defining illnesses, such as Septra for PCP, and there are drugs that can control and treat other AIDS-defining illnesses.

Are there treatments for HIV infection?

In addition to drugs and other treatments that can treat, control or prevent opportunistic infections, progress has been made in producing effective drugs that combat HIV directly. These drugs, often known as “combination therapies” or “the cocktail,” slow down the effect of HIV on the immune system by interfering with the replication of HIV. This form of therapy usually consists of a number of drugs taken on a strict timetable. Although these drugs are not easy to take and have side effects, when combination therapy is successful it can improve the health of people with HIV, sometimes causing remission of their symptoms in addition to reduced viral load (that is to say, reduced amount of HIV in their body), increased number of CD4 cells, and reduced likelihood of progressing to AIDS. Combination therapy does not work in everyone. The length of time that the drugs are effective against the virus varies, and drug resistance can set in, making the drugs ineffective.

Additionally, some people with HIV use complementary therapies such as acupuncture, vitamin supplementation, massage, etc. in addition to drug therapies to alleviate side-effects, reduce stress and improve immune function. Once thought to be an invariably fatal illness, we can no longer say that every person with HIV will become ill or die of AIDS. However, there still is no cure for HIV infection or AIDS.

Living with HIV/AIDS

Living with a serious, stigmatized and potentially life-threatening illness can be extremely stressful and difficult. Although someone with HIV may remain in good health for many years, there is a lot of fear, prejudice and misunderstanding in society about HIV/AIDS and the people who have this disease. People with HIV/AIDS may encounter hostility and rejection even from the people closest to them. They may lose their jobs, their homes or important relationships as a result of people’s negative attitudes about HIV/AIDS. Because of the stigma attached to HIV/AIDS, people may find it difficult to tell others about their diagnosis and may tell only a few close friends. The burden of secrecy can be hard to bear. Expressing your sexuality when you know that you could pass a serious infection on to someone else can also be extremely difficult. Many people find support through counseling or by participating in support groups for people with HIV/AIDS.

People with HIV/AIDS may also choose to make some adjustments in their lives to help them to cope with their diagnosis. They may try to stay healthy by eating good food, exercising or using complementary therapies. They may read lots of information about HIV and HIV therapies. Although living with HIV/AIDS can be a difficult and challenging experience, many people with HIV/AIDS live meaningful, satisfying and happy lives and contribute in important ways to their communities.



F. Timeline of Events

This timeline is intended to provide a historical context prior to attending *The Normal Heart*. It also sheds light on the Canadian experience that is not a subject of the play. Because the play captures a specific time and place (New York City in the early 1980s), this timeline extends beyond the timeframe of *The Normal Heart* to bring the issues of the play into a contemporary context and, we hope, inspire students to learn more about issues faced by people living with HIV/AIDS and the global AIDS crisis.

June 28, 1969: During a routine raid of Greenwich Village's Stonewall Inn (a bar with a mixed clientele including Black and Latino drag queens, students, homeless youth, hustlers and transgender patrons) by the New York City Police Department, a riot breaks out. Demonstrations start the following night and for subsequent nights throughout the week as New York's LGBTQ community – long the target of discrimination and persecution – declare enough is enough. "Stonewall" signals a new era of freedom and forever symbolizes the birth of the Gay Liberation movement.

1979: The epidemic later discovered to be AIDS becomes evident in Haiti.

1980: In Toronto's Mayoral election, gay rights emerge as a major issue, with Mayoral incumbent John Sewell endorsing openly gay alderman candidate George Hislop. The defeat of both Hislop and Sewell on **November 10** reflects the city's anti-gay climate and provides a police mandate to attack Toronto's LGBTQ community.

1981: On **February 5**, Toronto police raid the city's four largest bath houses, causing major property destruction, verbally abusing and publicly humiliating hundreds of gay men and conducting the largest mass arrest of citizens in the city's history. The incident becomes a catalyst for LGBTQ action, galvanizing the community.

In response to the raids, the Right to Privacy Committee (formed in 1979 in response to a raid of a small bathhouse called The Barracks in which fewer arrests were made) steps up its efforts, establishing a model of community organization, leadership and advocacy that will lay the groundwork for the soon-to-come fight against AIDS. Importantly, in later years, when San Francisco and New York baths are shut down, gay activists and Public Health officials in Toronto succeed in keeping the city's bathhouse doors open as they are recognized as an important forum to educate many gay men (particularly closeted gay men) about AIDS and safer sex.

Outbreaks of pneumocystis carinii pneumonia ("PCP") and a rare cancer, Kaposi's Sarcoma, are reported by doctors in Los Angeles and New York among gay male patients. On **June 5**, the Centers for Disease Control and Prevention ("CDC") in the United States publishes news of the outbreaks and the deaths of five gay men. The syndrome is first referred to as "gay cancer" and later, GRID ("Gay-Related

Immune Deficiency”). One month later, on **July 3**, the *New York Times* publishes an article: “Rare Cancer seen in 41 homosexuals.” (**Appendix A** of this Study Guide).

In New York, Larry Kramer invites 80 friends into his home to discuss these sudden deaths of otherwise healthy gay men and the Gay Men’s Health Crisis (“GMHC”) is formed.

In the fall, renowned Toronto-based newsmagazine and LGBTQ collective *The Body Politic* addresses the mainstream media’s portrayal of the emerging American epidemic, confronting what writers identify as homophobic and fear-mongering perspectives.

1982: In **March**, the first Canadian AIDS case is officially reported.

The syndrome is linked to blood and is identified not just in gay men but also in recent Haitian immigrants, women, male heterosexual injection drug users, hemophiliacs, blood transfusion recipients and babies. On **July 27**, GRID is renamed AIDS (“Acquired Immunodeficiency Syndrome”). Fourteen nations report AIDS cases.

In **November**, writer and professor Michael Lynch – soon to become one of Canada’s leading AIDS activists until his death in 1991 – publishes a controversial feature article in *The Body Politic* condemning the American gay community’s acquiescence to institutionalization, medicalization and fear-mongering in the press. He calls for a more personal, community-based approach that will lay the foundation for AIDS service and activism work in Canada.

1983: The United States reports 3,000 AIDS cases and over 1,000 deaths due to AIDS-related illnesses. Fifty-one cases are reported in Canada.

From **March to June** of this year, a group of Toronto activists, writers, health care professionals and social workers join forces in an effort to establish an ongoing AIDS committee to organize a coordinated response, and address the needs of AIDS patients and the community’s need for AIDS education. At a **July 19** press conference, the AIDS Committee of Toronto (“ACT”) makes its debut to the community.

At Paris’s Pasteur Institute in France, a team of scientists led by Dr. Luc Montagnier isolates the virus that may cause AIDS. They name it lymphadenopathy-associated virus (“LAV”).

1984: American Dr. Robert Gallo and his team confirm the discovery of the virus causing AIDS, claiming it as their own and renaming it human T-lymphotropic virus type III (“HTLV-III”). Montagnier and Gallo eventually agree to rename the virus human immunodeficiency virus (“HIV”), but their acrimonious ownership dispute continues for years.

Western scientists become aware that AIDS is widespread in parts of Africa.

The first needle exchange program is established in Amsterdam to help stop the spread of infection among injection drug users.

In San Francisco, the bathhouses are closed down. The community protests adamantly and, after a legal battle, they reopen.

In the US, AIDS rates have doubled within the year and over 6,000 cases are reported. About 150 cases are reported in Canada.

1985: *The Normal Heart* opens at New York's Public Theatre on **April 21**.

On **September 17**, US President Ronald Reagan publicly says the word "AIDS" for the first time.

In **November**, an HIV antibody test is developed in Canada. Community leaders fight for anonymous testing, though until any treatment becomes available, people are encouraged to not get tested for fear of stigmatization.

The first International AIDS Conference is held in Atlanta, Georgia. 2,000 people, primarily doctors and scientists, attend.

1986: 38,000 AIDS cases have been reported globally from 85 countries.

The CDC reports significant racial disparities in rates of infection, recognizing that Black and Hispanic Americans are developing the disease at three times the rate of Caucasian Americans. Among children, the disparity is even greater.

Toronto becomes the first city in Canada to develop an AIDS strategy including funding for community-based organizations.

The Ontario Human Rights Code is amended to protect against discrimination based on "sexual orientation."

In New York, Mayor Koch shuts down the bathhouses.

Dr. Jonathan Mann founds the World Health Organization's Global Program on AIDS, alerting international leaders to the crisis and establishing AIDS as a global human rights issue.

1987: The first anti-HIV drug – AZT – is approved by the US Food and Drug Administration ("FDA") and becomes available for people living with HIV and AIDS ("PHAs") in America. There is limited access to AZT for Canadian PHAs and, over the next several years in Canada, PHAs will fight for access to experimental treatments available elsewhere.

The Toronto People With AIDS Foundation (“PWA”) is formed.

In New York, Larry Kramer, ousted from GMHC, which he founded, joins with other activists to form the AIDS Coalition to Unleash Power (“ACT UP”) – a “nonpartisan group of individuals united in anger and committed to direct action to end the AIDS Crisis.” On **March 24**, ACT UP organizes its first demonstration at Trinity Church in the Wall Street business district, to demand affordable life-saving medicines be made available to patients, an end to discrimination against PHAs, AIDS education and a coordinated government response to the crisis.

In **April**, President Reagan delivers his first major speech on AIDS.

In **October**, hundreds of thousands of people take part in the March on Washington for Lesbian and Gay Rights. ACT UP’s now iconic “Silence = Death” logo gains visibility.

1988:

AIDS Action Now! (“AAN!”) forms in Toronto as a result of continuing frustration with government inaction and health care bureaucracy. The activist organization, led by Michael Lynch, pressures politicians and pharmaceutical companies to improve treatment for PHAs, secure access to experimental drugs, establish compassionate arms of clinical trials and guarantee PHA representation at all decision-making levels. Their conviction to remain volunteer-driven and independent of government funding allows AAN! political freedom not afforded charitable organizations like ACT or PWA. Over the years, through their direct action approach, AAN! is successful in bringing about major changes to government and pharmaceutical policy and action.

Michael Lynch’s AIDS Memorial is unveiled on Lesbian and Gay Pride Day, **June 26**. (See **Section I** for a field trip suggestion).

By the end of the year, 1,790 AIDS-related deaths have been reported in Canada.

1989:

Several ethno-cultural AIDS service organizations are established in Toronto, including the Black Coalition for AIDS Prevention (“Black CAP”) and the Alliance for South Asian AIDS Prevention (“ASAAP”).

Canada’s first needle exchange program is established in Vancouver.

The fifth International AIDS Conference is held in Montreal in **June**. AAN! and ACT UP members take over the opening ceremonies and AAN! Chair Tim McCaskell officially opens the conference, calling attention to the fact that Prime Minister Brian Mulroney, slated to open the conference, was about to make his very first public speech about AIDS in five years of being Prime Minister.

- 1990:** An estimated 8 million people are living with HIV and AIDS worldwide.
- Canada's Federal Health Minister Perrin Beatty announces the first National AIDS Strategy.
- 1991:** Developing from an AAN! initiative, the Community AIDS Treatment Information Exchange ("CATIE") is established.
- Darien Taylor and Andrea Rudd found Voices of Positive Women Support Services Ontario – funded primarily by the Ontario Ministry of Health and Health Canada – to serve the specific needs of women living with HIV.
- 1993:** In the US, the CDC, FDA and National Institutes of Health ("NIH") declare a joint statement that condoms are "highly effective for prevention of HIV infection."
- In the US Congress, the HIV Travel and Immigration Ban is passed and HIV status becomes a factor in determining permission to enter the United States.
- 1994:** AAN! successfully pressures the Ontario government to establish Ontario's Trillium Drug Program, granting drug treatment access to all PHAs, regardless of income.
- 1995:** AIDS is the leading cause of death for Americans ages 25 to 44.
- The United Nations establishes the Joint United Nations Program on AIDS ("UNAIDS").
- 1996:** New antiretroviral treatments are proven to be highly effective against HIV, substantially improving the lives of PHAs and fundamentally transforming the landscape of the epidemic in the developed world.
- New York Times Magazine, The Wall Street Journal and Newsweek* all run cover stories, hailing AIDS breakthroughs and the "end of the epidemic."
- In the US, AIDS is no longer the leading cause of death among all Americans ages 25 to 44. It remains, however, the leading cause of death of African Americans ages 25 to 44 and the third highest among women in this age group.
- In Ontario, there are about 950 new HIV diagnoses this year. Diagnosis continues at this steady rate over the next five years.
- Activists are successful in pressuring the Canadian government to renew the National AIDS Strategy.
- 1997:** An estimated 22 million people are living with HIV and AIDS worldwide.

- 1998:** The Supreme Court of Canada reaches a decision in the case of *R. v. Cuerrier* and in Canada non-disclosure of HIV status before engaging in activities that pose a “significant risk” of HIV transmission becomes a criminal offense. The courts, however, provide no definition of “significant risk” nor do they provide any guidelines for determining what “significant risk” might entail. The result is an inconsistent, subjective, case-by-case approach to interpreting the law.
- 2000:** One million people in Africa are newly infected with HIV this year. The UN Security Council discusses HIV/AIDS for the first time.
- 2001:** In Toronto, rates of infection among gay, bisexual and other men who have sex with men (“MSM”) are on the rise.
- 2002:** Ontario HIV diagnoses increase to about 1,100 per year and remain at this rate.
- 2003:** Insite, North America’s first legal supervised injection site, opens in Vancouver.
- 2007:** The Ontario Working Group on Criminal Law and HIV Exposure is formed by PHAs and representatives from community-based AIDS organizations, to oppose the expansive use of the criminal law to address HIV non-disclosure. By 2011 the Working Group is successful in convincing the Attorney General to establish guidelines for interpreting the law. (See **Appendix E** for relevant articles).
- 2009:** President Obama announces plans to lift the travel ban on HIV-positive people entering the United States, effective January 2010.
- 2010:** An estimated 34 million people are living with HIV and AIDS worldwide. 3.4 million of these are children and 50% are women. This year, about 2.7 million people become newly infected with HIV and 1.8 million people die of AIDS-related illnesses.
- Of these 34 million people, 1.3 million are reported in North America while 22.9 million live in Sub-Saharan Africa (comprising 68% of all people living with HIV worldwide). There are 1.2 million AIDS-related deaths in Sub-Saharan Africa this year (the vast majority of global AIDS-related deaths). In Africa, young women ages 15 to 24 are eight times more likely to be HIV positive than young men.
- In the United States, about 1 million people are living with HIV and AIDS. Over 75% of these are men. 61% of HIV positive men in America are gay, bisexual or other MSM. 42% of HIV positive Americans are Black, 33.3% are Caucasian and 21.4% are Hispanic and Latino.

Since the beginning of the epidemic, over 20,000 people in Toronto have tested positive for HIV. 87.5% of these people have been men. 82% of HIV positive men are gay, bisexual or other MSM.

In Toronto, MSM account for the group with by far the highest rate of transmission at 75%. In 2010, 13% of new infections were reported in women and 11% were reported among people from countries where HIV is endemic (countries where there are high rates of HIV). For women, 62% of all diagnoses were among women from countries with high rates of HIV.

An estimated 65,000 Canadians are living with HIV and AIDS. Nationwide, gay, bisexual and other MSM comprise 44% of new infections. 25% of new infections occur among heterosexual men and women not from countries where HIV is endemic, while 5.5% of new infections occur among heterosexual men and women from countries where HIV is endemic. Aboriginal Canadians continue to be over-represented, comprising 11% of all new infections in 2009.

PWA estimates that one third of Canadians living with HIV do not know they are infected.

Information for this timeline was gathered from the following organizations, media sources and publications: AVERT, AIDS Committee of Toronto, Toronto People With AIDS Foundation, Stephen Lewis Foundation, Toronto Star, Ontario HIV Epidemiologic Monitoring Unit, Pride Toronto, ACT UP, HIV & AIDS Legal Clinic (Ontario), Public Broadcasting Service's FRONTLINE, Ann Silversides, AIDS Activist: Michael Lynch and the Politics of Community (Toronto: Between the Lines, 2003).

G. Glossary of Terms

Prior to attending *The Normal Heart* it will be useful for your students to be familiar with the following words, people, places and concepts referenced in the play:

The New York Native

Published between 1980 and 1997, this was America's leading gay newspaper during the early 1980s and the first paper to publish anything about the epidemic later known as AIDS. In *The Normal Heart*, the character Mickey writes for the *Native* and his resistance to including specific references to sexual transmission symbolizes the *Native's* reputation for denying the sexual transmission of HIV.

The New York Times

One of the most prestigious English-language newspapers in the world.

Mayor Ed Koch

Former US Democratic Congressman for New York (1969–1977), Edward Irving Koch was the Mayor of New York City from 1978 to 1989. Though never mentioned by name, he is the mayor referred to in *The Normal Heart* and is significant to the history of AIDS due to his failure to act during the early years of the epidemic. Larry Kramer is among outspoken activists and artists who call attention to the fact that Mayor Koch is gay and closeted and that it was his fear of being “outed” that led to his inaction during the crisis. For more on this, watch Kirby Dick's excellent 2009 documentary film ***Outrage***.

Sexual Revolution

In the late 1960s sexual norms and expectations shifted radically to embrace the Hippie spirit of free love. Reacting to the rigid paradigms of the 50s and fuelled by activism around the Vietnam War and the Civil Rights and Women's Liberation movements, many people began to embrace gender and sexuality with a new spirit of openness and celebration. Many members of the LGBTQ community remember this time as the moment they discovered they were not alone – when they were finally free to acknowledge and celebrate their sexuality. Not surprisingly, many who had felt oppressed by strict gender and sexual mores (men and women, gay and straight), embraced their newfound sexual empowerment through promiscuity (frequent sex with many partners) not only as a personal choice, but also as a political statement. It is important to understand the characters in *The Normal Heart* as having emerged from this recent revolution. For more on this, watch the documentary films ***After Stonewall*** and ***Gay Sex in the 70s*** (See **Section K. Recommended Resources**).

Stonewall

On June 28, 1969, the New York Police Department conducted a routine raid of the Stonewall Inn – a Greenwich Village bar popular with a mixed clientele including Black and Latino drag queens, students, homeless youth, hustlers and transgender patrons. Harassment and discrimination against New York's gay and transgender residents was commonplace at this time and on this particular day, the people at the Stonewall Inn decided they'd had enough and a riot broke out. The next night and for several nights thereafter riots persisted, galvanizing New York's LGBTQ community. To this day “Stonewall” symbolizes the birth of the Gay Liberation movement and the anniversary of the Stonewall riots is celebrated with Pride parades and festivals around the world, including Toronto, which boasts the largest Pride parade in North America.

Christopher Street

This street in New York's Greenwich Village was the centre of urban gay life in the 70s and 80s. Lined with bars, shops and restaurants, it is referenced in the play as a place for cruising and meeting men for casual sex.

Fire Island

A popular upscale vacation spot for gay New Yorkers, located adjacent to the south shore of Long Island. Boasting beautiful beaches and hot clubs, it is considered the centre of gay summer life in New York.

Lesion

A small, darkened bruise-like spot on the skin. The lesions referred to in *The Normal Heart* are symptoms of a rare skin cancer called Kaposi's Sarcoma. The appearance of these lesions can be an early indicator of infection, as is the case with Felix in the play.

Hitler's Final Solution

This refers to Nazi leader Adolph Hitler's attempted genocide – his plan to completely eradicate the world's Jewish population – in what is known as The Holocaust. Ned references The Holocaust and draws a comparison between Hitler's annihilation of the Jews and the decimation of the gay population as a result of AIDS.

Dachau

A WWII Nazi concentration camp where Jews, political prisoners and others persecuted by the Nazis (including homosexuals) were interred and killed.

Bath houses/"the baths"

A social meeting place for gay men, typically a place for engaging in consensual, anonymous sex, frequently with multiple partners. Often housing a restaurant, gym, pool tables, spa services and water therapies, the baths were at their height of popularity for some gay men in the 1970s. Their presence in cities like New York, San Francisco and Toronto symbolized sexual freedom, and a degree of tolerance and civil liberty. They also, however, symbolized gay promiscuity and recreational drug use, so when AIDS began to spread through urban gay populations at alarming speed and medical experts suspected a link to sexual transmission, the question of whether or not to close down the baths became the subject of much debate and controversy. Toronto's own controversial bath house history pre-dates AIDS and is unique from the American experience due to the February 1981 incident known as the "Bath House Raids" in which Toronto police raided the city's four largest bath houses, causing major property destruction (about \$35,000 in damages) and conducting the biggest mass arrest in the city's history (approximately 300 people). The following evening a rally opposing police conduct was organized at the corner of Yonge & Wellesley Streets and Torontonians came out in unprecedented numbers that surprised even the organizers. It was a galvanizing moment for Toronto's LGBTQ community and the result was a more politicized, organized and unified gay community than the one depicted in Larry Kramer's picture of 1980s New York in *The Normal Heart*. To learn more about this fascinating and important moment in Toronto's history and its significant impact on Toronto's Gay Rights and HIV/AIDS activist movements, watch the 1982 documentary **Track Two**, directed by Harry Sutherland. It is available to view online for free at www.youtube.com/watch?v=iN4_8eurids.

Green Beret

This term refers to a member of the United States Army Special Forces. In the play, the character Bruce is a former Green Beret.

Donahue

Predating Oprah, Jerry Springer and other daytime TV talk shows, Phil Donahue was a major television personality whose famous show included panels on a variety of topics and issues, including gay rights. In the play, Ned refers to an upcoming appearance on the show, which is a nod to Larry Kramer's real-life appearance on the program, representing the Gay Men's Health Crisis ("GMHC") – one of the first talk shows ever devoted to the subject of HIV/AIDS.

Centers for Disease Control and Prevention ("CDC")

Located in Atlanta, Georgia, the CDC leads America's public health efforts to prevent and control infections and chronic diseases. It is an Operating Division of the United States Department of Health and Human Services. In *The Normal Heart*, characters voice their anger and frustration in the face of silence and inaction on the part of the CDC when they, on the front lines of the epidemic, are witnessing an obvious health crisis. For a fascinating alternate perspective on the early years of the epidemic, from a point of view within the CDC, watch the 1993 HBO feature ***And the Band Played On***, directed by Roger Spottiswoode (See **Section K. Recommended Resources**). For a more in-depth study, read the book upon which the TV movie is based – ***And the Band Played On: Politics, People and the AIDS Epidemic*** by Randy Shilts.

National Institute of Health ("NIH")

Another agency of the United States Department of Health and Human Services, the NIH is the country's leader in medical research and is the largest source of funding for medical research in the world. In the play, this is the agency to which Dr. Emma Brookner applies for research funding and is denied. The politically unpopular nature of HIV/AIDS under President Reagan is illuminated in the scene between Dr. Brookner and the Examining Doctor from the NIH, and we get a hint of how Reagan's staunchly anti-gay views negatively impacted early AIDS research and awareness.

"Tylenol Scare"

In 1982, seven people in the Chicago area died after taking Extra Strength Tylenol capsules that had been laced with potassium cyanide. Characters in the play remark on the contrast between the broad media attention surrounding this incident compared to the early media silence regarding the deaths of gay men as a result of what would later become known as AIDS. The comparison illustrates media bias and points to questions about what makes headlines and who gets represented in the media.

Jerry Falwell

Evangelical Fundamentalist Southern Baptist pastor and televangelist, in 1979 he founded the Moral Majority – America's hugely influential right-wing evangelical Christian political lobby group. Among its roster of hard-line issues, Falwell and the Moral Majority were staunchly anti-gay and fiercely opposed to allowing any rights for LGBTQ Americans. To this day, he remains a symbol of intolerance and bigotry.

H. Topics for Discussion and Classroom Activities

1. Theatrical Presentation

a) ISSUE-BASED THEATRE

Studio 180 is unique in that we produce plays that speak to socially and politically relevant issues. With your class, examine the company's Vision and Mission statements.

Studio 180's Vision – The experience of live performance inspires people to engage more fully in the world

Studio 180's Mission – To produce socially relevant theatre that provokes public discourse and promotes community engagement

- i) What do these statements mean to you? Does Studio 180's Vision resonate and have meaning? How effectively do you think the company's Mission serves its Vision? How does this production of *The Normal Heart* work toward fulfilling our Mission?
- ii) Why live theatre? What makes theatre an effective art form through which to explore social and political issues? Numerous excellent feature films, documentaries and books about AIDS are available, and throughout this Study Guide we recommend several of them for background and further study. What is unique about live theatre? Consider what is specific about your intellectual, emotional and communal responses to attending live theatre, compared to engaging in other forms of art, communication and media.

Hint: How does live theatre HUMANIZE issues and why is the humanization of social and political issues important?
- iii) Brainstorm issues that you would like to see turned into a piece of theatre. If you were going to see another play, or write a play yourself, what would you want it to be about? This question may serve as a jumping off point for **drama students** to begin their own issue-based theatre projects around stories and topics of particular relevance to them.

b) POINTS OF VIEW

One way we hope theatre will be an effective tool to explore important issues is through the portrayal of multiple perspectives or points of view.

How effective is *The Normal Heart* in exploring different sides of a story? Was the play even-handed? Did you feel that a multitude of opinions and points of view were expressed? Were the characters portrayed fairly? Which characters and stories were the most memorable? Which voices remained with you longest and why? Which moments had the greatest impact? Which characters surprised you? Did the play create questions for you regarding the characters or their circumstances? Did you form an emotional attachment to any of the characters? Who did you want to see more of? Did you disagree with what some of the characters were saying? What would you ask those characters, given the opportunity?

Further Study: Research the life and work of playwright Larry Kramer and the Gay Men's Health Crisis ("GMHC"). You will discover that *The Normal Heart* is highly autobiographical. Because of this, some critics feel the play is one-sided and those who oppose Larry Kramer's politics take issue with some of the arguments put forward in the play. What are some of Larry Kramer's key arguments and how are they portrayed through the play? Can you identify some of the people upon whom Kramer based his characters for *The Normal Heart*? How are some of their opposing opinions expressed? Dig deeper to find people who have disagreed with Larry Kramer and his politics. Why do you think *The Normal Heart* has been such a controversial play? Why was it a divisive force within the gay community?

c) DESIGN

How did the design of the production affect the presentation of the piece? How effective was the set in defining the space? What mood or ambience was created? How did colour, texture and space add to the theatrical experience? How was lighting used to create mood or ambience? How did lighting work to define space and setting? How did the set and the lights work in combination with one another? How was sound and music used to affect the presentation? How were costumes used to define characters? How did the costume designer make use of colour, texture and style?

How were the set, costumes, lighting, sound and props used to evoke the **period** of the play (early 1980s New York City)? Was the design **naturalistic** (a literal and accurate representation) or **abstract** (meant to evoke time and place)? **Drama students** should discuss the difference between the two approaches to design, focusing on the techniques used in this particular production.

d) THEATRE-IN-THE-ROUND

This unique staging format is used in Studio 180's production of *The Normal Heart*. It means that audience members are seated around the entire playing space. Most audience members will likely be familiar with a more traditional seating configuration whereby the stage or playing space is located on one end, with all the audience members facing it. Therefore, watching theatre in the round may be a new and surprising experience.

How is it different to watch a play in the round? How did the staging affect your experience of the play, your connection to the characters and your relationship to the space? What techniques did the actors use to include the entire audience in each moment? What techniques did the director use to stage the play in this formation?

e) "ART IS THE LIE THAT TELLS THE TRUTH" – Pablo Picasso

Discuss the meaning of this quotation and how it pertains to a play like *The Normal Heart*, which incorporates many historically accurate facts, statistics and events into a fictionalized narrative using characters based on real people.

What is the value of examining history through historical narrative (as opposed to documentary)? What is the value of telling a story through fictionalized characters who may be based on real people or who may even be composites of several real people?

2. Responsibility

a) PERSONAL AND COMMUNITY RESPONSIBILITY

What is our responsibility to ourselves and to our communities? *The Normal Heart* asks this complicated question within the context of AIDS. As a class, discuss the different ways in which characters are challenged to assume responsibility for themselves, for each other and for the gay community as a whole. When does personal responsibility (caring for a loved one) give over to political responsibility (standing up to the Mayor to demand rights and funding)? Can you think of examples from the play in which personal and political responsibility are intertwined? Use these quotations from the play as a jumping off point for discussion:

Ned: And every gay man who refuses to come forward now and fight to save his own life is truly helping to kill the rest of us.

Bruce: My boss doesn't know and he hates gays. He keeps telling me fag jokes and I keep laughing at them.

Ned: Bruce is in the closet; Mickey works for the Health Department; he starts shaking every time I criticize them – they won't even put out leaflets listing all the symptoms; Richard, Dick, and Lennie owe their jobs somehow to the Mayor; Dan is a schoolteacher; we're not allowed to say his last name out loud...

Bruce: But we can't tell people how to lead their lives!

Throughout the play, several characters debate the issue of “**coming out**” – revealing one's sexual orientation to friends, family, employers, etc. What different perspectives around this issue are expressed in *The Normal Heart* and why does each character hold his or her beliefs? Why might it be politically important for LGBTQ people to come out? Why might it be difficult to come out? Why is it more difficult for some than for others?

What responsibility do heterosexual or “straight” people have to combat homophobia? What responsibility do HIV-negative people have to support PHAs? Consider the following excerpt from a scene between Ned and his brother Ben:

Ben: My agreeing you were born just like I was born is not going to help save your dying friends.

Ned: Funny – that's exactly what I think will help save my dying friends.

What are some ways that heterosexual people can combat homophobia? *Examples: stand up to homophobic bullying, argue against homophobic statements made by parents and other relatives, initiate or join a Gay-Straight Alliance (“GSA”) at school.*

Do you need to be living with HIV in order to make a difference for those who are? What are some ways that you can contribute? *Examples: participate in fundraising events such as the AIDS Walk, educate yourself about HIV/AIDS and engage in dialogue with anyone spreading misconceptions or stigmatizing falsehoods, vote for politicians who support funding for AIDS Service Organizations and treatment programs.*

The following excerpts from the play can be used to guide the conversation:

Ned: We're being treated like shit. And we're allowing it. And until we force them to treat us otherwise, we get exactly what we deserve.

Ben: My agreeing you were born just like I was born is not going to help save your dying friends.

Ned: Funny – that's exactly what I think will help save my dying friends.

b) GOVERNMENT RESPONSIBILITY

When are governments responsible for taking care of their citizens? Do the actions, statements and omissions of individual politicians make a difference? When it comes to LGBTQ rights and freedoms, do the personal beliefs of our leaders matter? Did it matter that President Reagan did not publicly say the word AIDS until 1985 and only made a major speech about AIDS in 1987? Did it matter that Toronto Mayor Rob Ford did not attend a single Gay Pride event in spring 2011?

Begin with some of the following quotations from the play:

Bruce: It's not the city's responsibility to take care of us. That's why New York went broke.

Emma: Health is a political issue. Everyone's entitled to good medical care.

Ned: We have been trying to see the mayor for 14 months. It has taken us one year just to get this meeting with you and you are an hour and 45 minutes late.

Mickey: Mr. Keebler, sir, it is not illegal to discriminate against homosexuals.

Bring the conversation into a local and contemporary context with the help of one or more of the articles included as Appendices to this Study Guide:

Appendix B. Mayor Rob Ford and Pride Week

1. Toronto mayor's snub of Pride Week gives bigots cover to spew their bile
2. Mayor Ford mocked but not missed at Pride parade

Appendix C. Gay-Straight Alliances in Schools

1. Mississauga students to march for gay-straight alliance at Pride parade
2. Still no name for Catholic clubs against homophobia

Appendix D. Toronto's AIDS Funding

1. Ford votes alone against funding for HIV/AIDS programs
2. AIDS ACTION NOW! City Hall Deputation Letter

Appendix E. Criminalization of HIV Nondisclosure

1. HIV Criminalization
2. Prosecuting for knowingly transmitting HIV is warranted

3. Stigma and Discrimination

Thirty years have seen many changes and significant advances related to HIV/AIDS awareness and treatment. During the time of the play, a positive diagnosis might have felt like a death sentence. Today in North America, many PHAs live full, productive and relatively healthy lives due to major treatment advances. Yet two of the defining features of this disease remain the **stigma** and **discrimination** that accompany it.

In the early days of AIDS, stigmatization was based on fear and ignorance of a disease that nobody comprehended. Today we have access to accurate information about HIV and AIDS – the medical facts and the truths about transmission and prevention. Yet, ignorance and fear still prevail over many of our beliefs when it comes to AIDS and what it means to live with HIV.

Consider the following 2006 statistics regarding Canadian attitudes towards PHAs¹:

- 65% of surveyed Canadians believe that people with HIV/AIDS should not be allowed to serve the public in positions like dentists;
- 42% think people with HIV/AIDS should not be allowed to serve the public in positions like hairstylists;
- 26% would be very or somewhat uncomfortable working in an office where someone is known to be infected with HIV/AIDS;
- 49% feel uncomfortable using a restaurant drinking glass once used by a person living with HIV/AIDS;
- 26% feel uncomfortable even wearing a sweater once worn by a person living with HIV/AIDS;
- 20% do not believe in supporting the rights of people living with HIV/AIDS; and
- 13% feel afraid of people living with HIV/AIDS.

Take a look at the following excerpt from *The Normal Heart* in which Bruce describes the recent death of his lover Albert:

Bruce: His mother wanted him back in Phoenix before he died, this was last week when it was obvious, so I get permission from Emma and bundle him all up and take him to the plane in an ambulance. The pilot wouldn't take off and I refused to leave the plane – you would have been proud of me – so finally they get another pilot... The hospital doctors refused to examine him to put a cause of death on the death certificate, and without a death certificate the undertakers wouldn't take him away, and neither would the police. Finally, some orderly comes in and stuffs Albert in a heavy-duty Glad Bag and motions us with his finger to follow and he puts him out in the back alley with the garbage.

How is Albert treated differently from someone who might be dying from another illness such as cancer or heart disease? Despite advances in medical knowledge between then and now, why might the attitudes revealed by the above statistics prevail in our society? Why is it important to alter these attitudes and how can we create a community in which PHAs are treated with respect, dignity and equality?

¹ EKOS Research Associates Inc., HIV/AIDS Attitudinal Tracking Survey 2006: Final Report to Health Canada, March 31 2006, http://www.phac-aspc.gc.ca/aids-sida/publication/por/2006/pdf/por06_e.pdf

4. Media Response and Responsibility

a) SILENCE = DEATH

This ACT UP motto from the late 80s teaches us that by ignoring and/or remaining silent about AIDS, we allow for rising death tolls. The updated AIDS Action NOW! spin on this motto: ACTION = LIFE rings true today and reinforces the notion that the more we talk about HIV/AIDS and educate ourselves and our communities, the closer we will come to seeing the end of HIV/AIDS.

What is the media's responsibility to perform this educational and awareness-raising function in our communities? In *The Normal Heart*, how do different characters view the power and responsibility of mainstream media outlets such as the *New York Times*? How do different characters view the role of the gay press? How do different characters view the responsibility of individual gay journalists? The following quotations might help jump-start your class discussion:

Emma: This hospital sent its report of our first cases to the medical journals over a year ago. *The New England Journal of Medicine* has finally published it, and last week, which brought you running, the *Times* ran something on some inside page. Very inside: page 20. If you remember, Legionnaires' Disease, toxic-sock, they both hit the front page of the *Times* the minute they happened. And stayed there until somebody did something. The front page of the *Times* has a way of inspiring action.

Ned: No one here wants to write another article. I've talked to half a dozen reporters and editors and the guy who wrote the first piece.

Ned: Do you know that when Hitler's Final Solution to eliminate the Polish Jews was first mentioned in the *Times* it was on page 28. And on page 6 of the *Washington Post*. And the *Times* and the *Post* were owned by Jews. What causes silence like that? Why didn't the American Jews help the German Jews get out?... The American Jews knew exactly what was happening, but everything was downplayed and stifled. Can you imagine how effective it would have been if every Jew in America had marched on Washington? Proudly!

Bruce: I just think we have to stay out of anything political.

Ned: It is no secret that I consider the Mayor to be, along with the *Times*, the biggest enemy gay men and women must contend with in New York. Until the day I die I will never forgive this newspaper and this Mayor for ignoring this epidemic that is killing so many of my friends... And every gay man who refuses to come forward now and fight to save his own life is truly helping to kill the rest of us.

b) MEDIA SENSATIONALISM

In the play, Ned says to his brother:

Ned: You know the media always dramatizes the most extreme.

What does this statement mean to you? How does it apply to mainstream media portrayals of the LGBTQ community and HIV/AIDS? What is the relevance of this statement to the time of the play and how does it resonate today?

It is interesting to note a tension here when it comes to media reporting on HIV/AIDS. How can the media be accused of both ignoring *and* sensationalizing the same issue? Look to historical and contemporary real-life examples to engage in this discussion.

Further Study: Have students conduct their own research into media reporting on AIDS over the years. Collect articles and compare and contrast their contents. How do mainstream media outlets compare to LGBTQ publications? Some sources to consider are: the *New York Times*, the *Globe and Mail*, the *Toronto Star*, *The Body Politic*, the *New York Native* and *Xtra*. The **Canadian Lesbian and Gay Archives** will be a valuable resource. They are located right near Buddies in Bad Times Theatre: www.clga.ca.

Hint: You may encourage students to search for examples from the early years of mainstream AIDS reporting that could be described as “media panic.” In light of the sensational panic stirred up by the press, how did Toronto’s LGBTQ community respond? The *Body Politic* archives will provide some excellent examples. How did *The Body Politic* writers view the link between media panic around AIDS and homophobia? What arguments did writers put forth to combat these trends? Did the LGBTQ press over-compensate for this legitimate fear of homophobic panic and how?

Further Study: Can you think of other examples of media sensationalism that have stirred up panic within the community? Some suggestions include SARS, H1N1 and 9/11. Have students search for articles on these or other topics to analyze the effects of the media on public perception, fear and behaviour.

5. Sex Politics

The following excerpts from *The Normal Heart* capture the debate around sex and sex-positivity with regard to HIV/AIDS.

Ned: Do you realize that you are talking about millions of men who have singled out promiscuity to be their principal political agenda, the one they'd die before abandoning.

Bruce: I won't have anything to do with any organization that tells people how to live their lives... It's interfering with their civil rights.

Emma: ... if having sex can kill you, doesn't anybody with half a brain stop fucking?

Mickey: But not all of us feel that way. And we don't like to hear the word "promiscuous" used pejoratively... Sex is liberating. It's always guys like you who've never had one who are always screaming about relationships, and monogamy and fidelity and holy matrimony. What are you, a closet straight?

This is an especially complicated and sensitive discussion to have with students. When leading the conversation, here are some key points to keep in mind:

- As with all discussion of *The Normal Heart*, participation by students must be voluntary and no student should be singled out based on perceived notions of his or her sexual orientation or identity.
- Discussions about sexuality and promiscuity in *The Normal Heart* in particular and the early years of AIDS in general must keep in mind the context of the early 1980s, when the gay community was emerging from the recent battles won at Stonewall and the sexual revolution of the 1970s (See **Section G. Glossary of Terms** for details). For some gay men (represented by characters in the play), sex was considered a hard won political right and promiscuity was recognized as a vital part of gay identity.
- With regard to the context of the play, it is vital to remind students that at the time, nobody knew what we know now about HIV and transmission. People were only beginning to learn that AIDS was somehow transmitted sexually. Furthermore, because pregnancy was never a risk, talk of safer sex and condom use that is so familiar to us today were foreign concepts within the gay community. Therefore, we must take care not to view the play through the lens of what we know today.
- Teaching about the politics of sex and promiscuity is not the same as promoting promiscuity. You can lead a productive, mature conversation with students about the politics of sex and sexual identity without encouraging promiscuous or high-risk behaviour among students.
- Remember that the goal is to foster empathy and gain a deeper understanding of multiple points of view. Understanding history and the context of the play are fundamental to achieving this goal.

For more on this important and complex topic, we highly recommend the documentary films *After Stonewall*, *Gay Sex in the 70s* and *Sex Positive*, listed in **Section K. Recommended Resources**. Please note that these films contain sexually explicit scenes and imagery and must be pre-screened by teachers!

I. Field Trip Suggestion: The AIDS Memorial

Buddies in Bad Times Theatre is located in the heart of Toronto's "Gay Village." This area of the city is a culturally vibrant LGBTQ neighbourhood where bars, clubs, restaurants, cafés and shops abound. Most establishments prominently display rainbow flags – a symbol of LGBTQ Pride. Many of Toronto's LGBTQ community and HIV/AIDS organizations, including a number of *The Normal Heart* community partners, maintain offices in this neighbourhood.

Just blocks from the theatre, you can find Toronto's permanent AIDS Memorial, located in Cawthra Square – one block north of Wellesley Street East, between Church and Jarvis. The AIDS Memorial was the brainchild of AIDS activist Michael Lynch and began as a temporary memorial in 1989. In June 1993 this permanent memorial by architect Patrick Fahn was unveiled. If time permits, following the performance, we recommend that you include a visit to the memorial in the day's itinerary.

A visit to the memorial can be used as a time of quiet and personal reflection for students following the performance. Strolling the path and taking in the inscribed names forges a personal and human connection through 30 years of history, guiding us to the here and now.

Take the time to debrief on the experience. The following questions may help direct the conversation. Remember there is no right or wrong answer, only personal responses. Invite students to contribute to the conversation voluntarily, as they feel comfortable. For some students, five or ten minutes dedicated to private journaling may be a more appropriate follow-up activity.

- What impact does seeing the individual names have on you? Why do you think they were chosen to be the focus of the memorial?
- How is the memorial incorporated into its natural surroundings? Why do you think the artist chose this approach and what impact does it have?
- You have now experienced two different artistic approaches to AIDS – live theatre and visual art. What are the strengths of each medium? What are each able to convey? How do they each elicit an emotional response? What does each make you think about? How are they different in terms of their impact?
- Consider the ways in which you experience the play and the memorial individually and collectively. Is one a more individual experience? Is one a more collective or communal experience? How are you affected differently from a personal experience compared to a collective experience and why?
- How do the experiences of the play and the memorial impact and inform one another? Are there emotions, thoughts and experiences that are reinforced? Do you think a visit to the memorial without having seen the play may have been different and how?

J. Follow-Up Articles: Contemporary Issues

1. A Letter from Larry Kramer

The Normal Heart was first produced in New York in an off-Broadway run at the Public Theatre in 1985. In the spring of 2011 the play received its Broadway premiere. Playwright Larry Kramer wrote this letter and distributed it to audience members to let them know why he believes the play is just as relevant over 25 years later.

PLEASE KNOW: A Letter from Larry Kramer

Thank you for coming to see our play.

Please know that everything in *The Normal Heart* happened. These were and are real people who lived and spoke and died, and are presented here as best I could. Several more have died since, including Bruce, whose name was Paul Popham, and Tommy, whose name was Rodger McFarlane and who became my best friend, and Emma, whose name was Dr. Linda Laubenstein. She died after a return bout of polio and another trip to an iron lung. Rodger, after building three gay/AIDS agencies from the ground up, committed suicide in despair. On his deathbed at Memorial, Paul called me (we'd not spoken since our last fight in this play) and told me to never stop fighting.

Four members of the original cast died as well, including my dear sweet friend Brad Davis, the original Ned, whom I knew from practically the moment he got off the bus from Florida, a shy kid so very intent on become a fine actor, which he did.

Please know that AIDS is a worldwide plague.

Please know that no country in the world, including this one, especially this one, has ever called it a plague or acknowledged it as a plague, or dealt with it as a plague.

Please know that there is no cure.

Please know that after all this time the amount of money being spent to find a cure is still miniscule, still almost invisible, still impossible to locate in any national health budget, and still totally uncoordinated.

Please know that here in America, case numbers continue to rise in every category. In much of the rest of the world – Russia, India, Southeast Asia, Africa – the numbers of the infected and the dying are so grotesquely high that they are rarely acknowledged.

Please know that all efforts at prevention and education continue their unending record of abject failure.

Please know that there is no one in charge of this plague. This is a war for which there is no general and for which there has never been a general. How can you win a war with no one in charge?

Please know that beginning with Ronald Reagan (who would not say the word "AIDS" publicly for seven years), every single president has said nothing and done nothing, or in the case of the current president, says the right things and then doesn't do them.

Please know that most medications for HIV/AIDS are inhumanly expensive and that government funding for the poor to obtain them is dwindling and often unavailable.

Please know that the pharmaceutical companies are among the most evil and greedy nightmares ever loosed on humankind. What “research” they embark upon is calculated only toward finding newer drugs to keep us, just barely, from dying, but not to make us better or, god forbid, cured.

Please know that an awful lot of people have needlessly died and will continue to needlessly die because of any and all of the above.

Please know that the world has suffered at the very least some 75 million infections and 35 million deaths. When the action of the play that you have just seen begins, there were 41.

I have never seen such wrongs as this plague, in all its guises, represents, and continues to say about us all.

Larry Kramer

Distribute the letter to students after they have seen the play. You may ask students to read the letter independently and spend ten minutes journaling about their personal responses. Or ask different students to read sections of the letter aloud as a group and engage in a class discussion. Here are some suggested questions to help guide the conversation:

- After seeing the play, did any of the facts or statistics in this letter surprise you?
- Can you draw parallels between the writer of this letter and the character of Ned Weeks? What about the voice of the writer reminds you of Ned? What are the differences?
- Does any of the information contained in this letter inspire you to learn more about certain aspects of HIV/AIDS (such as global action to fight AIDS, pharmaceutical companies, the history of government action/inaction)?
- Does the issue of HIV/AIDS remind you of any other issues such as other health epidemics or local or global crises?

2. AIDS Activism: Past, Present and Future

Emma: I hear you've got a big mouth.

Ned: Is big mouth a symptom?

Emma: No, a cure.

The following articles by leading Canadian AIDS activists from two generations provide an excellent foundation for understanding the history and the future of Canadian activism in the area of HIV/AIDS. If time is limited, select one article on which to focus your class discussion.

The first article, "Power to the People," by pioneering AIDS activist Tim McCaskell, provides a clear and thorough history of community mobilization in the face of the epidemic. It is an excellent resource for students wishing to learn specifically about the struggle for treatment access and the ways in which PHAs revolutionized how governments, pharmaceutical corporations and the medical industry responded to health care needs in the face of AIDS.

The second article, "How I would put an end to HIV," by AIDS activist and York University Grad student Alex McClelland, captures the realities of HIV today and puts forth a bold vision for the future. Students will be inspired by the work of this community leader, not much older than they are, and his article is a perfect resource for addressing contemporary issues around AIDS, beyond those identified in *The Normal Heart*.

If time permits, have students read both articles and in your debriefing address the generational differences between the two writers. How has the evolution of the epidemic altered their perspectives? How is the younger activist able to build on the work of his predecessors?

ARTICLE 1:

Power to the People

A look back at the issues, struggles and victories that defined the early age of AIDS activism in Canada

by Tim McCaskell

Early to Mid-'80s: Igniting Hope

In the early 1980s, the nightmare of AIDS broke like a tsunami over gay communities in Canada's major cities. Young, healthy men were suddenly and inexplicably dying across the country. No one knew the cause of the epidemic, and even after the identification of HIV in 1984, there was ongoing controversy over the role of the virus in the syndrome. No cure existed for the underlying immune dysfunction, and treatments for the opportunistic infections that came in its wake were largely ineffective.

With medical science impotent and in disarray, gay communities were largely thrown back on their own resources. They established organizations offering support and counselling, set up hospices to care for the dying and, once HIV had been identified, launched prevention campaigns urging safer sex. But with "only" marginalized groups such as gay men dying, government efforts, what little there were, tended to be restricted to preventing the virus from spreading to the "general population."

Some 25 years later, it's illuminating to trace the course of events that ensued – the outcry, struggles and victories of early AIDS activists in their efforts to force key changes within the medical establishment, the pharmaceutical industry, the government and the health care system – and to look at the role that treatment information played in those struggles.

In 1987, impatience with government inaction and lack of research for treatments and a cure finally erupted in the US. The AIDS Coalition to Unleash Power in New York ("ACT UP NY") emerged, quickly leading to the formation of chapters across the US. Canadians soon followed ACT UP NY's example of in-your-face activism, drawing on the women's health movement's healthy skepticism of the medical establishment and the strategies and tactics of lesbian and gay liberation, with its demonstrations and street theatre.

That same year, Kevin Brown, a founder of the BC Persons With AIDS Society ("BCPWA"), began lobbying the federal government for speedy access to AZT, which had just been approved as the first treatment for HIV infection in the US. And in early 1988, inspired by the example of American activists, AIDS ACTION NOW! formed in Toronto. Most of AAN!'s activists were HIV positive. Treatment quickly emerged as a key issue, as did criticism of the Public Health approach, which was so focused on prevention that it ignored the needs of those already infected.

When AAN! published its first treatment information broadsheet, Treatment AIDS, and distributed thousands of copies at Toronto's Lesbian and Gay Pride day in June 1988, there was little distinction between "alternative" and mainstream approaches, and minimal scientific rigour. The medical establishment might have warned against raising "false hopes," but to activists, trying anything made more sense than waiting around to die.

Information and Access

In this context, treatment information was the foundational element of treatment activism. If they were going to mobilize and fight back, people needed hope. The idea that treatment, or even a cure, might be within reach helped combat the resignation and despair that had seized many people living with HIV/AIDS (“PHAs”), convinced that they faced an imminent death sentence. It also raised expectations and focused attention on the barriers to treatment – government red tape and inaction, and lack of research and information. The virus might be incurable but, according to treatment activists, people were not so much dying of a virus as they were dying of neglect and indifference. That, we could do something about. The goal was to empower PHAs to make demands on the health care system, the government and the pharmaceutical industry.

At this point, activists confronted the incomprehension of most people in positions of authority. It took time for doctors to recognize that their patients often knew as much as they did about the new and mysterious disease, and that a much more collaborative approach was necessary. Governments were blind to the fact that the glacial pace of standard drug approval and a laissez-faire approach to research were inappropriate in the face of crisis. The pharmaceutical industry was befuddled by unprecedented demands for immediate access to experimental treatments and trial designs that didn’t use PHAs as expendable guinea pigs. They were all oblivious to what BC Civil Liberties Association President John Dixon began to call the “catastrophic rights” to treatment for those facing major illness.

Pentamidine was a case in point. When the drug was used in a nebulizer that turned it into a fine mist breathed directly into the lungs, pentamidine trials in the US had shown dramatic results in preventing PCP (*Pneumocystis pneumonia*), at the time the major AIDS-related killer. But the drug, although available in most hospital pharmacies, had not been approved for aerosolized use in Canada and Canadians could not get access. Activists demanded the opening up of the federal Emergency Drug Release Program (“EDRP”) to allow PHAs access to a range of experimental treatments from around the globe.

Also, in the face of increasing demand for action, a placebo-controlled trial of aerosolized pentamidine was finally set up in Canada in 1988. It would enroll 750 participants, all of whom had had at least one bout of PCP and who were therefore at high risk for a second attack. But half the group, in a placebo arm, would receive nothing. The deaths in that group would be the measure of success of the drug among those who received treatment. AAN!’s first public action was a demonstration that marched on Toronto General Hospital, site of the trial in that city. The demonstrators demanded that the trial be halted and the treatment be made available to those who needed it. To hell with the regulations, lives were at stake.

The fall of 1988 saw a federal election. AIDS activists across the country dogged the ruling Progressive Conservatives for their lacklustre efforts against the epidemic. The message got through. Although the Conservatives were re-elected, one of the first announcements made by the new Health Minister, Perrin Beatty, was that Canadians would be able to access experimental AIDS treatments, including pentamidine, through EDRP (now renamed the Special Access Program, “SAP”). The unethical pentamidine trial was halted and a whole range of new treatments became available.

If the government had begun to move, the pharmaceutical industry was still slow to respond. It took a month-long picket of the Bristol-Myers offices in Toronto by a mother demanding access to ddI for her seriously ill son, international news coverage and the arrest of AAN! activists occupying its offices in the summer of 1989 before the company gave in and agreed to make the drug available on a compassionate basis.

Foundations of an Infrastructure

Treatment information had proved itself a powerful weapon in mobilizing PHAs to demand change, and in the spring of 1989 AAN! set up the local Treatment Information Exchange (“TIE”) in Toronto to make scientifically reliable information on cutting-edge treatments available. TIE took on the publication of AAN!’s *Treatment Update / Traitement Sida*, a low-budget summary of breaking treatment information written by Sean Hosein.

But activists also recognized the limitations of grassroots, local efforts in spreading the word. With what’s now called the Special Access Program open for business, AAN! joined the Canadian AIDS Society to demand that the federal government establish a national treatment registry to provide information about treatment options and strategies for PHAs and their doctors across the country. When Health Minister Beatty announced funding for the country’s first national AIDS strategy in April 1990, he also included funding to set up the registry.

But announcements and implementation are quite different animals. A year later, after several false starts, there was still no national treatment registry in sight. Rather than wait on the government, activists decided to do it themselves. In February 1991, AAN!’s TIE project became the Community AIDS Treatment Information (“CATIE”). As an independent, charitable organization, CATIE would be able to raise funds to put in place a credible infrastructure to gather, evaluate and distribute treatment information, at least on a local level.

By now the government, the research establishment and the pharmaceutical industry could no longer ignore the voices of PHAs. When the Canadian HIV Trials Network (“CTN”) began functioning in 1991, it included a Community Advisory Committee made up of activists from across the country. The Committee has veto power over any research protocol considered by the CTN. One of the great legacies of treatment activists was that they successfully pushed for the involvement of PHAs at all levels: public policy, research design, hospital advisory boards, AIDS service organizations (“ASOs”) and more.

New Access Issues

By 1992, the face of AIDS was changing and so, too, were the strategies employed by treatment activists. The epidemic was no longer confined to the gay community. More women were now infected. Treatment activists, many of them women themselves, struggled with understanding how the new therapies coming on line were affecting women’s bodies since most had only been tested on men.

As well, as scientific understanding of AIDS deepened and more drugs and treatments were tested, enrollment in clinical trials of new antivirals became a major mode of access to treatment for PHAs. Suddenly, the design and ethics of clinical trials became a serious concern. In early 1992, AAN! published the information booklet *AIDS and HIV Drug Trials in Canada: What you need to know*. A major AAN! demand was that all trials

include a compassionate arm so that those seeking treatment could participate in trials knowing that they were receiving the drug and not a placebo.

Increasingly, cost was also becoming a factor. Most provinces had originally established programs to pay for the early antivirals, but as time went on, the growing number of newer antivirals and treatments for opportunistic infections were not covered. In Ontario and Quebec, for example, more and more PHAs without adequate private drug coverage were forced to stop work and go on welfare in order to be eligible for a provincial drug card to pay for their medications. In a dramatic video broadcast shortly after his death in January 1993, AAN! Chair James Thatcher indicted the Ontario government, whose failure to establish a catastrophic drug program had prevented him from accessing treatments he needed to stay alive. The following year, in the face of persistent pressure, the government finally relented and established Ontario's Trillium Drug Program.

The role of treatment information continued to be an integral part of the struggle for access throughout the first half of the 1990s. Knowledge that options existed empowered PHAs to demand more from their doctors. It increased pressure on governments to cover the cost of expensive therapies and mobilized PHAs to demand that the pharmaceutical industry take their interests into account in the design of clinical trials.

Mid-'90s to 2005: Managing Service

In the summer of 1995, CATIE received the federal government contract to implement the national AIDS treatment information service [formerly called the national treatment registry], which had been floundering in successive agencies since its announcement in 1990. Much had changed since AAN! had made its first proposal for a national treatment registry in 1989. As CATIE struggled with transforming itself from a local to a national, bilingual organization over the next year, AIDS treatment in Canada was being transformed by the introduction of the first protease inhibitors. For the first time, effective combination therapies – highly active antiretroviral therapy (“HAART”) – and the dream of AIDS as a “chronic manageable infection,” a concept popularized by AAN!’s George Smith in 1988, were real possibilities.

But the emergence of new therapies also had unexpected results. As the dying diminished, so did the perception of AIDS as a crisis. One of the major activist fights at the International AIDS Conference in Vancouver in July 1996 was to demand that the government renew the National AIDS Strategy with its dedicated funds for prevention, services and research. The Chrétien government had previously announced its intention to let the strategy lapse.

A second development was that treatment information had become much more complex. The “exchange” of information among peers originally envisioned was increasingly being superseded by the technical demands of information technology – managing, evaluating and disseminating huge amounts of complex information.

Finally, many of the demands for access by AIDS activists had been met. The Special Access Program was functioning and experimental drugs were available. Most clinical trials now included compassionate arms. And the provinces with the largest numbers of PHAs had programs in place to cover the cost of medications for those who were uninsured. As well, many of the original activists had died and many of those who

survived were exhausted. The sense of crisis within the gay community diminished and groups like AAN! were unable to incorporate activists from the newer and often even more marginalized sectors of the population – injection drug users, Aboriginal communities, new immigrants and refugees, youth – now affected by the epidemic.

One group that continued to pressure both government and the pharmaceutical industry on behalf of PHAs on a national level was the Canadian Treatment Action Council (“CTAC”). Founded in 1996, CTAC worked to orchestrate activists’ participation in pharmaceutical advisory committees and ensure that trial design and management committees were knowledgeable and accountable to the community. Today, CTAC provides policy and research related to treatment access directed at both pharmaceutical companies and government, and conducts related skills-building activities targeting CTAC members and PHAs across Canada.

The growing professionalization required of groups such as CATIE in order to effectively manage and evaluate huge amounts of data was accompanied by a decline in traditional activism. Treatment information became increasingly understood as a service to help patients and doctors deal with a range of confusing choices, rather than an incitement to public action. One group that has bucked this trend, however, still combining treatment information and in-your-face treatment activism, is Montreal’s LIPO-ACTION! Since its launch in 2003, the group has used demonstrations, street theatre and lobbying to raise awareness and demand access to new therapies to combat lipodystrophy.

Back to the Future

The growing complexity of AIDS treatment and the increasing marginalization of communities now affected by the virus have meant that power and expertise is once again shifting away from “patients” back to medical professionals and institutions.

In response, many ASOs are deepening the work of providing treatment information to their local communities, usually with electronic links to CATIE. BC Persons With AIDS Society (“BCPWA”), for example, established its own Treatment Information Project (“TIP”), and its bimonthly publication *Living Positive* regularly combines information on treatment issues with practical advice on the challenges of living with HIV, news and political issues.

In Montreal, the Comité des Personnes Atteintes du VIH du Québec (“CPAVIH”) holds regular forums on treatment issues, as does the Toronto People With AIDS Foundation, which established a treatment resources position as early as the late 1980s. Thanks to the work of the Committee for Accessible AIDS Treatment, that position now includes a component to assist individuals temporarily without access to HIV medications — people with a temporary lapse in coverage, refugees and others. [This program grew from earlier efforts to “recirculate” medications from PHAs who died or weren’t able to tolerate them, to others without access.] As well, a new Ethnoracial Treatment Support Network has been established in Toronto. The network trains peer treatment counsellors from immigrant and refugee communities to work with other HIV-positive community members struggling with cultural, linguistic or legal barriers to accessing treatment.

This last focus illustrates a major challenge facing the treatment information movement in Canada – how to target efforts to make highly complex and technical information about treatment options available to increasingly diverse, marginalized populations from a variety of cultural and linguistic backgrounds. One size can no longer fit all.

The next decade will decide if the treatment information movement, born out of a ferment of patient empowerment and entitlement, will be able to continue to evolve to meet the challenges emerging from the changing face of AIDS. If the resilience that this movement has shown since the first dark days of the epidemic is any indication, however, there are grounds to hope that it will continue to thrive until a cure is found and the AIDS epidemic finally becomes history



Tim McCaskell is a longtime gay activist in Toronto. He was a founding member of AIDS ACTION NOW! in 1988, and a member of the Ontario Advisory Committee on HIV/AIDS for over a decade.

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This information was provided by CATIE (Canadian AIDS Treatment Information Exchange). For more information, contact CATIE at 1-800-263-1638 or info@catie.ca.

ARTICLE 2:

How I would put an end to HIV

by Alex McClelland

I was recently asked to present at the 20th Canadian Association of HIV Research (“CAHR”) Conference for the session “Ending HIV by 2020: Mission Possible?” along with Dr. Rupert Kaul, Dr. Ahmed Bayoumi, Dr. Patty Daly and Dr. Michael O’Shaughnessy. The awesome folks at PositiveLite have asked me to turn my presentation into a blog post. So I have reworked my thoughts to present them here. I’m very happy to finally be posting on this site, as I read it all the time and love it!

CAHR asked each presenter to present our thoughts on how we would end HIV. I want to first acknowledge that this task was intimidating to undertake and was very humbling for me.

I’ll discuss how we can stop HIV incidence by the year 2020 from a community perspective – a rather daunting task, especially for a white guy when there is so much diversity in our response. However, gay men like me continually make up a disproportionate portion of this epidemic, so it is appropriate that I was tasked with this exercise.

Speaking from a community perspective is challenging. While “community” does imply that we are working together, which I like, it is a highly complex term, which is often imposed by outsiders onto groups of divergent people who may only have one thing in common (like being HIV-positive for example). So one of the consequences is that the term community conceals more than it reveals. I needed to acknowledge this before moving on to the fun stuff.

Preparing for this, I conducted a mini research survey and sent it out to my colleagues, allies and friends. In the end I had 62 respondents and 30 some pages of input from my “community,” half of whom are living with HIV.

So in this piece, I acknowledge that I am the one who wrote it, but it draws widely on the collective knowledge of those who completed the survey.

One other caveat before beginning: I am **not** going to discuss what is needed to end HIV by 2020. But I am going to address where we are going astray and where we need to go.

After almost 30 years we know a hell of a lot about how to end HIV incidence, about what we need to do to turn this epidemic around in Canada. We have many effective tools and strategies, frameworks and a huge number of assets, leaders and resources.

Activists have known what we need to do to end HIV for a long time. Ugandan activist Beatrice Were once wrote:

“...as a woman living with HIV, I am often asked whether there will ever be a cure for HIV/AIDS, and my answer is that there is already a cure. It lies in the strength of women, families and communities who support and empower each other to break the silence around AIDS and take control of their sexual lives.”

Were is speaking from a context where the primary mode of transmission is through heterosexual sex and where women are most vulnerable. But her sentiment is applicable in Canada where we also know what we need to do to end HIV. But just because we know doesn't mean it's happening.

To have the greatest impact our response should look like a balance of research, services and social change. But in fact our Canadian response today is focused primarily on research and service provision. As a result we are failing on a whole bunch of levels. Let me explain by using the education sector and drug policy as case studies to highlight this gap in knowledge and action.

The Education Sector

We have known for a long time that we need a comprehensive sexuality curriculum in our schools that includes a focus on sexual diversity and which addresses homophobia. But we have widely failed at implementing this consistently or effectively in Canada. HIV transmission knowledge among our students is lower today than it was in the 90s. In a 2003 study (yes its old, but Canadian research is slim in this area) "*approximately 66% of Grade 7 students and 50% of Grade 9 students did not know that there is no cure for HIV,*" and "*some students have the misconception that there is a vaccine available to prevent HIV*" (Council of Ministers of Education in Canada, 2003).

Action to address this gap would require advocating the Council of Ministers of Education for policy change to mandate consistent curriculum on comprehensive sexuality education across Canada. This hasn't happened and we are failing to ensure this human right is realized.

Drug Policy

We know that ending the war on drugs, viewing drug use through a public health, not a criminal lens and ensuring the provision of harm reduction interventions to people who use drugs leads to decreased HIV and Hep C transmission rates. For example InSite, the safe injection site in Vancouver, has been shown to reduce HIV and Hep C infections, support health-seeking behaviour and reduce deaths from overdose, but has failed to get government support on ideological grounds.

What we have learned is that there are limits to where science can take us as our Federal leaders and institutions are not supporting or carrying out this work. As a result, we are losing ground. An example of this failure is the Public Health Agency of Canada. While at a community level we understand harm reduction as a staple public health program, our national Public Health institution is not allowed to acknowledge or practice this most basic tenet of public health.

"The Vienna Declaration is inconsistent with Canada's National Anti-Drug Strategy... Canada will not support the document... The government of Canada believes that the best way to address the public health consequences of injection drug-use is to prevent people from using illicit drugs in the first place." (Charlene Wiles, Public Health Agency of Canada, 2005)

Politics has prevailed despite how much science we promote.

Props to all those working to produce this great data, but without a systemic advocacy force to push back against ideologically driven policy-makers the right to health for people who use drugs is still not realized. Another fail.

That was my cursory overview of the gaps in our response. Why are we failing in these areas and why is there this gap around addressing social change?

Well, our range of options, our possibilities and our imaginations are limited because of a number of factors constraining our efforts:

Neo-liberalism and the bio-medicalization of everything.

HIV is the first global epidemic to come about under neo-liberalism. As a result, our response efforts have been continually constrained to fit within this ideology. One that favours individualism, competition, efficiency, corporate rationalities, privatization, decreased spending on social services such as health and education. An ideology opposed to addressing social and structural issues that drive HIV. This kind of thinking doesn't value human rights, because human rights are not a commodity that can be traded in the market. Neo-liberalism views people as rational agents who live in a vacuum, a view that simplifies HIV risk and responsibility. Which is why approaches trying to change individual behaviour have prevailed. If they would only just use condoms, right?

As you may have noticed, I was the only person asked by CAHR to present during this session who doesn't have a Dr. in front of their name. The reason I point this out is because for me it nicely illustrates what forms of knowledge are privileged in the response to HIV. In Dennis Altman's book from 1994 *Community and Power*, he stated:

"What has become a regular division of discussion at both international and national conferences into four tracks Basic Science, Clinical Care, Epi, Social Response – has come to suggest that this is the natural way of conceptualizing the epidemic... which has the effect of other topics, particularly with political or cultural content appear peripheral..."(Dennis Altman, *Power and Community*, 1994).

This quote is still relevant today; our conferences are still structured in this hierarchy of knowledge. So I propose that at the next CAHR conference we throw this hierarchy out and integrate all the tracks together based on topics not disciplines.

During the CAHR conference, American social scientist and policy-maker Judy Auerbach said that when looking at how to undertake research we should let the questions drive the method and not the other way around.

But with the HIV response our methods are predetermined as defined by neo-liberalism and biomedicine and do not challenge these world orders.

In Canada, we have around 120 community-based organizations that work on HIV. Most of these are AIDS Service Organizations ("ASOs"). Have you ever questioned why we have so many organizations that only provide services or conduct research?

Imagine for a minute that we had this many AIDS Social Change Organizations. Imagine if our efforts were dedicated upstream at the root causes of social inequality, at

challenging harmful public policy and government inaction. This is not meant in disrespect to the many amazing people who do vital work in these organizations.

I'm sure all the ASO Executive Directors will say: "Well Alex, we can't do advocacy work – we are not allowed to." And yes this is true; a majority of our organizations can't even say the word "advocacy" let alone do it.

Organizations with charitable status can only use 10% of their budgets on advocacy work. But if the 10% rule isn't working for us then we should work to change it. Or we should develop a new mechanism to systematically fund advocacy and social change work. We can do better and we can be more creative.

An example of successful activism is Ontario's drug coverage program, Trillium. This program covers the cost of my \$1,700 a month HIV meds. And today we take this for granted, but why does this program exist? Because of AIDS ACTION NOW! who fought our government in Ontario to make this happen in the 1990s. Just imagine how much the quality of life has improved for people in our province as a result of this piece of social change work?

So wrapping up, to turn around HIV we need to acknowledge the constraints we are under and reflect on how they can create greater inequities and limit what is possible in our work. We also need to reflect on how through the regimes of neo-liberalism and bio-medicine we can end up reproducing harmful practices, which are counter to the goals of this response.

I am envisioning a better world in which equity and rights are our goals as opposed to maintaining our funding and not wanting to offend anyone, a world where our response values and supports sustainable social change work. When I talk about social change, I am talking about working to challenge harmful policies, laws, and practices that those in power are inflicting on our communities. I'm talking about working to end poverty, challenging homophobia, and doing antiracist and decolonizing work. I'm talking about realizing basic human rights, rights, which are still out of reach for lots of Canadians.

Social change work is hard, scary for some, and not always popular. But it is a vital component of what we need to do if we want to honestly and appropriately change how we respond to HIV. We need to be brave. We need to reorganize our resources and we need to slowly chip away at the systems constraining our work. This is what we need to do to end HIV incidence by 2020.

Pretty easy, right? Let's get to work.

Thank you to Nicole Greenspan and Adrian Guta who were great supports in the development of this presentation.

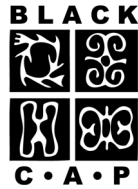


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3. HIV/AIDS in Black, African and Caribbean Communities

The following is information provided by the Black Coalition for AIDS Prevention.



The Black Coalition for AIDS Prevention (“Black CAP”) is a Toronto-based HIV/AIDS organization that provides Black, African and Caribbean people living with or at risk for HIV/AIDS with health related supports. Our organization works to reduce HIV/AIDS in Toronto’s Black, African and Caribbean communities and enhance the quality of life of Black people living with or affected by HIV/AIDS. We have a 20-year history of working within Toronto’s Black communities to prevent new HIV infections and support people living with HIV/AIDS. Our office is located at the corner of King and Victoria streets in downtown Toronto and we are mandated to serve people from across the GTA. We deliver a range of prevention, outreach and support programming that contribute to our mission. Our Support Department provides services that are meant to improve the quality of life of people living with HIV/AIDS (“PHAs”) by providing counselling services that address the full range of challenges they experience. Our Prevention and Outreach Departments work to increase knowledge of the HIV and STI related risk and gives people tools and information to reduce the likelihood of HIV infection.

HIV/AIDS continues to be a pressing issue for members of Toronto’s Black communities. The following are important reminders of the depth of this issue:

- An estimated 26,627 people are living with HIV in Ontario: of these 4,878 are Black, representing 18% of those infected
- About 25% of people who are newly diagnosed with HIV in Ontario are Black
- Of Black people living with HIV in Ontario, about 60% are men and 40% are women
- Only 56% of Black people in Ontario with HIV have been diagnosed, which means that 44% are presently unaware of their HIV status
- Between 2009 and 2010, HIV diagnoses among Black people in Ontario increased by 20% and rates of HIV testing in the community decreased
- In 2009, almost 50% of women diagnosed with HIV in Ontario were Black: in Toronto two thirds of women living with HIV are Black
- 77.5% of HIV diagnoses among Black people in Ontario were in Toronto (58.8%) and Ottawa (18.7%).

Founded in 1989, Black CAP continues to work under the guidance of its motto, ‘Because All Black People’s Lives Are Important’: which stands as a reminder of the importance of our commitment to our communities. With the incidence of HIV/AIDS rising in Toronto’s Black communities, and issues such as HIV related stigma and discrimination, homophobia, criminalization, anti-Black racism, immigration, poverty, and other barriers to social inclusion continuing to present significant obstacles to members of our communities, we believe that our motto and mission are more important than ever.

Even though HIV has existed in our community since the 1980s many of our clients experience significant levels of HIV stigma from their family, neighbours, employers, and communities. HIV stigma refers to prejudice, discounting, discrediting, and discrimination directed at people perceived to have AIDS or HIV, and the groups and communities with whom they are associated. Due to HIV stigma and denial many people in Toronto's Black community may be discouraged from using services available in their own communities. Caribbean and African communities in Toronto are often small and located in specific geographic areas, creating a sense that "everyone knows everyone" and that news about HIV infection or sexual orientation will be shared in the community or travel "back home." This perceived lack of personal privacy may contribute to the denial of HIV, the fear of disclosure, and an inability to access services in the community. As a result, organizations like Black CAP are called on to provide services to support PHAs to deal with the stigma they experience.

Black CAP is especially interested in the issue of the criminalization of nondisclosure of HIV status. This is becoming a bigger issue for our clients and community given that individuals who do not disclose their HIV status prior to sex could be charged with assault, sexual assault, attempted murder or murder. In Canada today there is a trend toward using the criminal justice system over other effective public health approaches. This approach does not recognize that most PHAs practice safer sex and usually disclose their status to their partners. This approach also increases levels of stigma by portraying PHAs as criminals and adds to prejudice and discrimination against those living with HIV. In addition, it further criminalizes Black Canadians. Criminalization is an important issue that Black CAP and our partners are working to address through public education, research and policy work. Black CAP believes that methods, other than the criminal justice system, are much more appropriate tools to address this issue. We support the effectiveness of HIV prevention and risk-reduction education and other proven public health approaches to address HIV transmission. Such approaches include education, consistent condom use, and regular HIV testing.

At Black CAP we know that contracting HIV does not mean that one's life is going to end. Many of the clients, staff and volunteers involved in Black CAP have been living with HIV and AIDS for many, many years. The reality is that, thanks to highly effective treatments, most people living with HIV/AIDS can expect to have a typical lifespan and to stay healthy for a long period of time when taking appropriate treatment and medication. The best way to live a long and healthy life with HIV is to seek support and to find information. The reality is that the best defense against HIV requires three things, community support, information and good healthcare and treatment. We recognize that an HIV diagnosis can be both stressful and overwhelming. In fact, many people who are newly diagnosed feel that it is the end of their life, many of us at Black CAP would say that it is the beginning of a new life. To learn more about Black CAP or to donate or volunteer please visit our website at www.blackcap.ca



4. HIV/AIDS and Aboriginal Canadians

The following information is collected from the Canadian Aboriginal AIDS Network 2009 study, Our Search for Safe Spaces: A Qualitative Study of the Role of Sexual Violence in the Lives of Aboriginal Women Living with HIV/AIDS. It provides insight into some of the factors contributing to the alarmingly high and growing rates of HIV infection among Aboriginal Canadians, particularly young women. The complete document can be downloaded from the Ontario Aboriginal HIV/AIDS Strategy website: www.oahas.org/Resources/resources.html

In recent years, the face of the HIV/AIDS epidemic in Canada has changed significantly. What was once a disease concentrated among men who have sex with men is now increasingly an epidemic among women. Aboriginal women are experiencing a disproportionate burden of new infections in this country (Shannon et al. 2008: 912). According to the Public Health Agency of Canada (“PHAC”) (2007). Aboriginal women represented 48.1% of all positive HIV test reports among Aboriginal people between 1998 and 2006. Although Aboriginal people represent just 3.8% of the Canadian population, in 2005, estimates indicated Aboriginal people were about 7.5% of all prevalent HIV infections (PHAC 2007; Mehrabadi et al. 2008).

The alarmingly high levels of HIV infection reported among Aboriginal women are believed to be the result of entrenched marginalization and discrimination within Canadian society, the ongoing legacy of colonialism and oppression. Complex, interwoven factors of gender, class, and ethno-culture, both systemic and particular, have increased exposure to HIV among Aboriginal women. One of the most pervasive and damaging outcomes of these factors is the widespread occurrence of sexual violence and exploitation of Aboriginal women and girls. Research has shown that sexual violence and HIV/AIDS are deeply interrelated and often reinforcing.

The links between gender-based violence (“GBV”) and HIV/AIDS are well established and sometimes referred to as ‘twin epidemics’ (Kathewera-Banda et al. 2005; Mamam et al. 2000). Both GBV and HIV/AIDS operate in a cycle of reinforcing exposures. Sexual violence against women may lead to immediate infection with HIV. As well, exposure to violence, particularly child sexual abuse, places women at increased risk of poor mental health outcomes, which may result in high risk activities such as sex work, multiple sexual partners and substance use (Farley et al. 2005; Heise et al. 1999; UNAIDS 2003). GBV can also make it difficult for women to negotiate safer sex or adhere to medicine regimens; it can also inhibit their overall ability to lead a healthy and dignified life. What’s more, HIV positive women may face increased violence from their partners, families and/or communities as a result of stigma and fear surrounding their HIV status (ibid. 2003).

Aboriginal women are affected by HIV in ways that are unique to both their gender and cultural identities. Determinants rooted in the impacts of colonization have created entrenched poverty, social marginalization and unresolved trauma, which can increase their exposure to HIV/AIDS. For these reasons, Aboriginal women’s position at the intersection of GBV and HIV/AIDS must be understood in the context of a colonized peoples (Ship & Norton 2001).

The numerous layers of stigma faced by AWHAs create barriers to health services, leaving many AWHAs and their children without formal supports (Health Canada 1996; Ship & Norton 2001). Many Aboriginal women have reported racial discrimination and a perception of racism in their dealings with the health care system (Adelson 2005; Browne & Fiske 2001; Bucharski et al. 2006; Tang & Browne 2008; Vernon 2001). Cultural and gender stereotypes such as “wag, squaw, dirty Indian, [and/or] black bitch” are examples of Aboriginal women’s accounts of their negative experiences with service providers (Bucharski et al. 2006: 729). It is also a common perception that service providers in health care settings to presume that Aboriginal women are sex workers and drug users (ibid et al. 2006).

Ship and Norton (2001: 28) argue that stigmatization and barriers to service experienced by Aboriginal women are pushing them into a position of “extreme isolation.” Community rejection, systemic racism and sexism, socio-economic marginalization, and a history of trauma and gender subordination related to colonialism have placed AWHAs in a position of extreme marginality and vulnerability.

A lack of accessible, culturally sensitive care presents a significant barrier to obtaining health services for many Aboriginal people living with HIV/AIDS; however, the nature of barriers to traditional health services differs along gender lines (CAAN: 2005a; Bucharski et al. 2006; Ship & Norton 2001). Results from the CAAN report, Canadian Aboriginal People Living with HIV/AIDS: Care, Treatment and Support Issues (2005b) suggest that AWHAs are less likely than Aboriginal men to know of the existence and location of Aboriginal health services and are less likely to have the logistical support to access such services (CAAN 2005a). It has been suggested that, due to a lack of culturally sensitive service options Aboriginal women may be less likely to pursue early testing (Bucharski et al. 2006; CAAN 2005; Ship & Norton 2001). Within the last few decades, Aboriginal communities have begun to control their own health services; however, Aboriginal women have expressed the need for gender analysis (Mann 2005).

The pathways through which experiences of childhood abuse lead to future violence in the lives of Aboriginal women with HIV are multifaceted and interwoven. However, to develop successful programs and policies, we must attempt to understand this complex web of determinants.

Childhood Experiences

Abuse and neglect in childhood create both direct and indirect exposure to future violence among Aboriginal women. In the most general sense, abuse of any kind damages children’s self esteem, their belief in a just world and their trust in other human beings. Research in this area has linked experiences of childhood abuse, victimization and witnessing the abuse of others with poor mental health in general and the development of post-traumatic stress disorder in particular (Choi, Reddy, Liu, & Spaulding, 2009; Martinez, Hosek, & Carleton, 2009; Meade, Kershaw, Hansen & Sikkema, 2009). According to researchers, physical and emotional abuse can cause disruptions in the development of children’s self esteem that can become evident later in life as either extreme passivity/apathy or intense aggression, both of which create exposure to violence (Brayden, Deitrich-MacLean, Dietrich, & Altemeier, 1995; Finzi-Dottan & Karu, 2006; Maxwell, 2003; Parker & Benson, 2004).

Sexual abuse has an even more profound impact, often destroying children’s trust in not only the abuser, but in people generally (Walker, Holman & Busby, 2009). Children who

are sexually abused do not learn how to establish sexual boundaries as they grow older, thereby, perpetuating their exposure to further sexual exploitation and victimization (van Roode, Dickson, Herbison & Paul, 2009). In an effort to cope with the abuse, children frequently dissociate from the experience and can develop dysfunctional sexual practices in which they assume a passive role (Bowyer, 2009; Frost-Pineda, 2008). The role of neglect in creating exposure to violence lies in its capacity to undermine children's self worth and create a deep need to be loved and valued; sometimes to the extent that they will tolerate future violence (Bowyer, 2009; Chambers & Potter, 2009; Merrick, Litrownik, Everson & Cox, 2008).

The connection between the legacy of residential schools and the abuse of Aboriginal children has proven to be substantial and destructive (Cuomo, Sarchiapone, Ciannantonio, Mancini & Roy, 2008; Million, 2000). In many cases, addictions and the subsequent abuse and neglect of children can be traced to the trauma experienced by parents and grandparents who attended residential school (MacLachlan, 2007; Miller, 2003). Similarly, foster care appears to be a potential threat to the physical, emotional and sexual well being of Aboriginal children, as many have reported abuse within this context (Gramkowski, Kools, Paul, Boyer, Monasterio & Robbins, 2009; Jacobs, 2008; Onyezia, 2009).

Overarching the impact of abuse and neglect on the emotional, physical and spiritual health of Aboriginal children is the role of drugs and alcohol as a means of coping with the trauma of these experiences (Chambers, 2005; Hamburger, Leeb & Swahn, 2008; Hayatbakhsh, et al, 2009; University of Montreal, 2008). The research literature has established a strong relationship between the mental health impacts of trauma and the misuse of drugs and alcohol (Haller & Miles, 2003; Haller & Miles, 2004). As an example, Walker, Scott and Koppersmith (1998) found a link between the severity of child sexual abuse and the extent of future alcoholism. Others have discovered that witnessing the addictive behaviours of one's parents can normalize the activity, encouraging children and youth to use drugs and alcohol, particularly to deal with life stress (Holt, Buckley & Whelan, 2008; Werner, Alain Joffe & Graham. 1999).

Social Determinants

Disadvantages such as lack of opportunities, poverty, racism and punitive social services are mutually reinforcing and heighten women's exposure to violence. Racism against Aboriginal women perpetuates racially motivated physical and sexual violence, as well as diminishing women's opportunities for education and employment, as well as their sense of optimism about the future (Doyle-Bedwell, 2008; Dylan, Regehr & Alaggia, 2008; Hoagland, 2007; Tyagi, 1999; Wallace, 2007). Lack of opportunities can lead to poverty, dependency on others, including social services or men, and potential involvement in the sex trade (Gowans, 2001; Kwesiga, Bell, Pattie & Moe, 2007; Kurz, 1998; Petterson & Friel, 2001; Rice, 2001; Scott, London & Gross, 2007).

The stress and/or depression caused by these circumstances, and often exacerbated by past trauma, induces some women to use drugs and alcohol (King & Chassin, 2008; Reed, Anthony & Breslau, 2007; Weaver, Haston Turner & O'Dell, 2000). Unfortunately, social services, intended to assist vulnerable women, repeatedly generate additional stress by creating a punitive environment, rather than a nurturing one (Cooper Altman, 2007; Haight, Shim, Linn & Swinford, 2007). Women are essentially left alone to attempt to deal with past and current traumas, thus diminishing their capacity to safeguard against future violence.

Gender Inequities

The physical, economic and social impact of inequitable power relations between Aboriginal women and their male partners is well documented in the literature (Comaskey & Marquis, 2001; Liodakis, 2009; McGillivray, 2001; Stirbys, 2008). In the context of Aboriginal women with HIV, particularly those who are living in conditions of poverty and/or with addictions, partner selection can be somewhat limited (Rotheram-Borus, Desmond, Comulada, Arnold & Johnson, 2009). As a result, women may partner with men who tend to be more violent and exploitive of women and who attempt to control them through money and/or drugs. In some instances, men encourage their female partner to use drugs, thereby facilitating her eventual addiction and perhaps even her subsequent work in the sex trade (Dalla, 2001; Earls & David, 1990; Women of the World, 2004).

The interpersonal violence (physical, emotional and sexual) of these relationships leads women to fear men in general and their partners in particular (Avakame, 1998; Haskell & Randall, 1998; Sev'er & Cheryl, 2004). This fear facilitates further violence in two ways: 1) women are often reluctant to leave an abusive relationship because they fear retribution by their partner (Hamby & Gray-Little, 1997; Richards, Rollerson & Phillips, 1991; Shoos, 2003), 2) in an attempt to circumvent violence, women may become excessively passive with men, yet, this passivity can actually create further exposure to abuse/exploitive men (Castano, 2006; Ruiz-Perez, Mata-Pariente & Plazaola-Rothenberg, 2003).

One of the most perplexing factors deterring women from leaving abusive relationships is love for the abuser, which does little to diminish further violence. Some researchers and clinicians believe that this attachment emerges from neglect in childhood (Feiring, Taska & Lewis, 1998; Mcgee, Wolfe & Olson, 2001). Child physical and sexual abuse may also increase women's tolerance for violence, making them less likely to leave an abusive partner. Many people do not understand this form of attachment, however, failing to appreciate the role childhood experiences play in forming women's self concept and relationships.

Self Concept

The role of self concept in heightening Aboriginal women's exposure to violence cannot be overstated. Cumulative trauma, particularly by caregivers and loved-ones, often devastates women's self esteem and frequently leads to self blame. When linked to sexual abuse, addictions and the effects of HIV medication, women also may suffer from negative body image (Clark & Griffi n, 2008; Price, 2005; Treuer, Koperdak, Rozsa & Furedi, 2005). The anger, resentment and betrayal women experience can lead to poor mental health and/or addictions, which, along with self blame, negative body image and diminished self esteem, can lead to lack of self care (e.g., physical, mental, spiritual, sexual and emotional health) (Peltzer & Hobbs Leenerts, 2007). When women feel badly about who they are, they are more likely to become exposed to violent men and are less likely to appreciate their own value and their right to live without exploitation and violence (Bulanda & Majumdar, 2009; Chuang, Liebschutz, Horton & Samet, 2006; van Roode, Dickson, Herbison & Paul, 2009).



5. How HIV and AIDS Impact Women

Increasingly, women are making up a greater percentage of new HIV/AIDS diagnoses. As we have learned throughout this Study Guide, there is a strong correlation between HIV/AIDS diagnoses and high levels of discrimination and marginalization in society. For many reasons, women are often among the most marginalized and disempowered members of society, leaving them especially vulnerable to HIV transmission. Some examples of the factors contributing to women's vulnerability include higher rates of poverty, incidence of violence, sexual violence and gender inequality.

Human rights activist and HIV/AIDS support worker Marvelous Muchenje has provided the following summary of contributing factors to the growing rates of HIV infection among women, together with the specific medical, psychological and social impacts of HIV/AIDS on women.

Gender-Based HIV Statistics: Canada

- By the end of 2008, 10,799 positive HIV tests were reported among adult females in Canada.
- There are an estimated 14,300 women living with HIV/AIDS in Canada – a 17% increase from the 12,000 estimated for 2005.
- Before 1999, women represented 11.7% of all positive HIV test reports. By 2006, women represented 27.8% of all positive HIV test reports.
- The following are estimates of reported positive HIV tests among women by race/ethnicity. Precise percentages are unavailable as neither Ontario nor Quebec report test results based on race/ethnicity. Note how in the cases of Aboriginal and Black women, HIV rates are grossly disproportionate to the population:
 - 42% – Aboriginal (according to the 2001 Census Aboriginal people make up approximately 3% of the population)
 - 33% – Caucasian
 - 18.8% – Black (according to the 2001 Census, Black people make up approximately 2% of the population)
 - 2.1% – South Asian, West Asian and Middle Eastern
 - 1.6% – Southeast Asian and East Asian
 - 0.8% – Latin American
 - 0.5% – Other

Social and Psychological Factors Contributing to HIV Risk to Women

- **Violence against women** is a widespread problem locally and globally. For many women the **threat and fear of violence** may put them at risk for contracting HIV because it prevents them from:
 - Advocating for safer sex practices such as using condoms
 - Being able to consent to sexual relationships
 - Disclosing HIV positive status
 - Seeking treatment
 - Accessing health care

- All women experience **gender inequality** differently based on cultural and religious norms and individual circumstances. For some women, these inequalities may severely restrict the power they have over their lives and relationships including sexual relationships.
- **Injection drug** and **heavy substance use** are linked to higher risk of infection. These higher risk behaviours are prevalent among the more marginalized members of our communities. As experts have said, *the more pain people are in, the more they self-medicate*.
- **Poverty** is another prevalent issue faced by women locally and globally, leaving many women especially vulnerable.
- **Lack of sex education**
- These and other factors help contribute to high rates of **low self-esteem** among many women, leaving them increasingly vulnerable.

Biological Factors Contributing to HIV Risk to Women

- Compared to male genitalia, female genitalia/mucosal tissues have an increased surface area
 - Vaginal/cervical tissue is easily traumatized
 - Women's anal tissue is also easily traumatized
 - Presence of other STIs can increasingly compromise vaginal/cervical tissue
- Bacterial vaginosis: the most common vaginal infection. HIV positive women are three times likelier to transmit HIV to their sexual partner if they also have bacterial vaginosis. Having bacterial vaginosis also increases a woman's risk of acquiring HIV.

Health Needs and Concerns for Women Living with HIV in Toronto

- Along with the physical symptoms associated with HIV, there are **mental health** conditions including depression, anxiety, dementia and Post-Traumatic Stress Disorder.
- **Pregnancy** and family planning are unique concerns for women that can be complicated by HIV-positive status.
- Weakened immune systems leave HIV-positive women vulnerable to **chronic yeast infections**.
- As a side effect of anti-HIV drugs, women are more likely than men to experience **Lipodystrophy** in the abdomen and breasts. Lipodystrophy refers to abnormal central fat accumulation that can lead to disfigurement, an increase in cardiovascular problems, depression, low self-esteem and poor body image.
- Women are more likely than men to experience hypersensitivity to certain anti-HIV drugs, resulting in **side effects** such as severe rash, fever, nausea, abdominal pain, vomiting and diarrhoea.
- As women age, they are increasingly vulnerable to bone thinning and HIV-positive women are especially at risk, which can lead to **osteoporosis and bone fractures**.
- HIV positive women are at high risk of developing **anaemia** which has been linked to HIV disease progression and an increased risk of death.
- HIV positive women have a higher risk of contracting **Human Papillomavirus ("HPV")**, which causes genital warts and can lead to cervical cancer.

- As women age and estrogen levels decline, all women have a heightened risk of developing **cardiovascular disease** and HIV-positive women are especially vulnerable.
- Due to biological factors, women are at higher risk for contracting **STIs** than men, making HIV-positive women especially vulnerable to these increased health risks.
- HIV positive women are more likely to experience frequent and more severe outbreaks of **herpes**.

Challenges and Barriers to Meeting Health Needs of Women Living with HIV

- Racism, gender discrimination, homophobia and HIV-related stigma are all pervasive and interconnected forms of stigma and discrimination that cannot be unlinked. The impact on women is far-reaching:
 - Silence and secrecy around HIV status
 - Delays in accessing treatment and care, resulting in poorer outcomes once care is accessed
 - Fears about confidentiality when accessing services
 - Inability to disclose status to service providers and intimate partners
 - Lack of access to information and services resulting from gender and cultural dynamics within personal relationships, lack of family and community support, inflexible and ineffective service delivery models, lack of culturally and linguistically appropriate programs, language and literacy barriers
 - Many women live in poverty, leaving them vulnerable and lacking the support they need to access resources, information and services

Strategies to Strengthen Access to Health Care, Treatment and Support Services

- Involve women in decision-making as part of their routine care
- Recognize the location of power in service provider/patient relationships
- Strengthen and implement effective referral systems
- Provide HIV/AIDS and health care information in ways that women understand, taking into consideration literacy and language skills
- Link HIV transmission and risk to the broader determinants of health (such as poverty, discrimination, equality and access to care)



6. HIV/AIDS and Injection Drug Users

In **Section E.2. HIV & AIDS: The Basics**, we provided basic information about the high risk of contracting HIV for injection drug users:

Another common way that HIV is transmitted is through a puncture from a needle that has already been used by someone else and has not been cleaned. When people who are injecting drugs share their “works” (needle, cooker, etc.) it is easy to get HIV. It is also easy to get other infections, such as hepatitis C, from sharing your works.

You have learned that today in North America, many PHAs live healthy and full lives, as a result of major advances in medicine and the access to treatment that activists have won. However, people in Canada still die of AIDS related illnesses. Frequently, they are people who use injection drugs and have contracted both HIV and hepatitis C. These individuals tend to be among the most marginalized members of our society.

Teaching about the dangers of injection drug use and a “harm reduction” approach to reducing instances of infection such as HIV is not about teaching students “safer ways to use drugs.” Nor is the purpose to assign blame to people who engage in higher risk behaviour. On the contrary, the goal here is to foster empathy and begin to understand why some members of our community may be more vulnerable than others. Once we achieve a degree of empathy and understanding, only then can we begin to take the appropriate steps towards achieving change on a systemic level and putting an end to HIV transmission.

We know that sharing needles puts one at risk for contracting HIV. So why do people still share needles? And what are the best, most proven methods of helping people make better, safer choices?

The following documents are included to help you begin this very complicated conversation and to offer a foundation for class discussion. They are provided by the British Columbia Ministry of Health, from Harm Reduction: A British Columbia Community Guide.

What is Harm Reduction?

The International Harm Reduction Association (2002) describes harm reduction as: Policies and programs which attempt primarily to reduce the adverse health, social and economic consequences of mood altering substances to individual drug users, their families and communities, without requiring decrease in drug use.

Harm reduction is a pragmatic response that focuses on keeping people safe and minimizing death, disease and injury associated with higher risk behaviour, while recognizing that the behaviour may continue despite the risks. At the conceptual level, harm reduction maintains a value neutral and humanistic view of drug use and the drug user. It focuses on the harms from drug use rather than on the use itself. It does not insist on or object to abstinence and acknowledges the active role of the drug user in harm reduction programs.

At the practical level, the aim of harm reduction is to reduce the more immediate harmful consequences of drug use through pragmatic, realistic and low threshold programs. Examples of the more widely known harm reduction strategies are needle exchange programs, methadone maintenance treatment, outreach and education programs for high risk populations, law enforcement cooperation, medical prescription of heroin and other drugs, and supervised consumption facilities.

There are many reasons why people engage in higher risk behaviour and not all people are able to make the immediate changes necessary to refrain from such behaviours. Harm reduction is a set of non-judgmental policies and programs which aims to provide and/or enhance skills, knowledge, resources and support that people need to live safer, healthier lives. It encourages people to build strengths and to gain a sense of confidence.

Harm reduction can help move a person from a state of chaos to a state of control over their own life and health. For some people, abstinence is the most feasible way to reduce harm. Interventions that aim for abstinence and for safer drug use both have a place within harm reduction. The key is to balance abstinence-based programs with those that reduce harm for people who continue to use drugs.

Harm reduction saves lives and improves quality of life by allowing drug users to remain integrated in society. The alienation and marginalization of people who use drugs often compound the reasons why they engage in unsafe drug use. Harm reduction also reduces health care costs by reducing drug-related overdose, disease transmission, injury and illness, as well as hospital utilization.

Harm reduction benefits the community through substantial reductions in open drug use, discarded drug paraphernalia, drug-related crime, and associated health, enforcement and criminal justice costs. It lessens the negative impact of an open drug scene on local business and improves the climate for tourism and economic development.

Common Concerns About Harm Reduction

Concern: Harm reduction enables drug use and entrenches addictive behaviour.

This is rooted in the belief that drug users have to hit “rock bottom” before they are able to escape from a pattern of addiction and that harm reduction protects them from this experience. For those who do not want to quit, cannot quit, or relapse into drug use, harm reduction can effectively prevent HIV, hepatitis C and other drug-related harms. Harm reduction is often the first or only link that drug users have to the health and social service system and, as such, it is a gateway to addiction treatment. Harm reduction services increase the possibility that drug users will re-engage in broader society, lead productive lives and quit using drugs, instead of contracting and transmitting infectious diseases and/or succumbing to drug overdose death.

Concern: Harm reduction encourages drug use among non-drug users.

This is based on the notion that harm reduction “sends out the wrong signal” and undermines primary prevention efforts. Some feel that helping drug users stay alive, reduce their exposure to risk and become healthier may encourage non-users to regard drug use as safe and to want to start using drugs. This view underestimates the complexity of factors that shape people’s decisions whether to use drugs. It also ignores numerous scientific studies that have found no evidence that the introduction of needle exchange or other harm reduction programs increases drug use.

Concern: Harm reduction drains resources from treatment services.

Harm reduction interventions are relatively inexpensive and cost effective. They increase social and financial efficiency by interrupting the transmission of infectious disease at a lower cost, rather than waiting to treat complications of advanced illness at a much higher cost.

Concern: Harm reduction is a Trojan Horse for decriminalization & legalization.

Harm reduction attempts to deal with the harms from drug use as it occurs within the current global regulatory regime. Some advocates of harm reduction want to see changes in the way governments have been attempting to control the trade and use of currently illegal drugs; others do not. Harm reduction itself is neutral regarding the question of legalization. The philosophy of harm reduction applies equally to alcohol and tobacco use, which is legal in most countries.

Concern: Harm reduction increases disorder & threatens public safety & health.

Often referred to as the “honey pot effect,” this concern assumes that harm reduction programs will attract drug dealers and compromise the safety and well being of the surrounding community. Evidence has conclusively demonstrated that harm reduction programs do the opposite. They have a positive impact on public health by reducing the prevalence of blood borne viruses such as HIV and hepatitis C. Needle exchange programs often recover more needles than they distribute, which means fewer used needles discarded publicly in the community. Supervised injection facilities reduce the number of public injections by providing a safe, indoor alternative to open drug use. Protocols between police and harm reduction service providers ensure drug trafficking laws are enforced – open drug dealing is discouraged, while drug users are encouraged to access needed services.

Needle Exchange Programs

Needle exchange programs (“NEPs”) distribute sterile syringes and collect used syringes. They operate on the principle that every injection should be performed with sterile equipment. The use of non-sterile injection equipment increases the risk of HIV, hepatitis C and bacterial infections which are difficult and costly to treat. In Canada, injection drug use is currently the single most important route of hepatitis C transmission. Blood borne pathogens are also a public health threat to others, including spouses, partners and unborn children of injection drug users.

NEPs have been scientifically demonstrated to reduce risks of contracting HIV and hepatitis C. Studies have shown that they can decrease the risk of contracting HIV by as much as 50 to 80%. NEPs serve as a collection point for used needles and can minimize the number of publicly discarded needles that can be found in parks, playgrounds and school yards. NEPs also serve as an entry point for drug users to access critical health and social services, including referrals to detoxification and treatment services when desired. NEPs have not been associated with increases in crime. The best results are achieved by creating good access to sterile needles and other injection equipment.

NEPs are an established international best practice in health. In BC, the Ministry of Health and the BC Centre for Disease Control have direct responsibility for NEP policies and guidelines related to effective and safe implementation. In 2004/05, approximately 6.38 million needles and syringes were exchanged across the province.



7. HIV/AIDS in Canada's South Asian Communities

In 1989 the Alliance for South Asian AIDS Prevention (“ASAAP”) was founded in Toronto.

ASAAP is a community-based, non-profit, charitable organization committed to providing health promotion, support, education and advocacy in a non-discriminatory manner for those who identify as South Asian living with and affected by HIV/AIDS.

As we have discussed throughout this Study Guide, some of the greatest challenges to living with HIV and AIDS result from misconceptions, stereotypes and stigmatization. The characters in *The Normal Heart* confront various forms of discrimination and stigmatization. Representing the early days of the AIDS epidemic in North America, however, we can note that these characters are all white males and many are middle class. In a multicultural and diverse city such as Toronto, not all people experience stigmatization and discrimination in the same ways. By the late 80s, when more and more of Toronto's ethnocultural groups began acknowledging the spread of HIV within their communities, organizations developed to respond to the specific needs of their community members.

In June of 1999, ASAAP underwent an extensive community research project and published a report entitled, *Discrimination & HIV/AIDS in South Asian Communities: Legal, Ethical & Human Rights Challenges: An Ethnocultural Perspective*. The full report can be found at <http://www.asaap.ca>. The brief excerpt below outlines some of the specific needs of PHAs within Toronto's South Asian communities and points to key community education priorities.

South Asian Communities of Toronto

Among the total of 1,338,090 visible minority people living in the Toronto area, 24.7% or 329,840 are South Asian (Census 1996). South Asians are defined as those who trace their origin, directly or indirectly to the countries of India, Pakistan, Sri Lanka, Bangladesh, Burma, Nepal, Bhutan or the Maldives. South Asians speak many languages including Gujarati, Urdu, Farsi, Pashto, Punjabi, Tamil, Hindi, Malayalam and Bengali. The faiths practiced by South Asians are diverse as well. Hinduism, Islam, Sikhism, Christianity, Buddhism, and Jainism form the primary faith groups which are represented in different proportions among South Asians in the various countries in the Indian subcontinent and the diaspora. South Asians in Toronto reflect the cultural, religious, ethnic and class diversity of South Asian communities from around the world. It is not uncommon for people within the community to identify themselves with their religion, their geographic region of origin and their linguistic backgrounds. Religious organizations play a powerful and dominant role in the lives of many South Asians. Community life centres around the family, extended-family networks and the practice of religion.

The ideals of cooperation and family loyalty, which require that family obligations take precedence over personal interests, are basic to many South Asian communities. This translates into a strong collective culture or a value system characterized by a strong sense of community, dense social networks, and an emphasis on familial relations.

In addition to supports and services provided to South Asians through their mosques, temples, gurudwaras, churches, jamaatkhans, and other places of worship, cultural organizations are a vital part of South Asian life. South Asian communities in Toronto are served by a number of ethno-specific health, settlement, and social service agencies. South Asians are able to access services from many mainstream organizations as well, depending on their ability to speak English and/or fit with admissions criteria or benefit from the program style/format. Racism often prevents people of colour from accessing appropriate health and social services. South Asians who are among the various new immigrants and refugees to Canada, often feel the keenest impact of racism because they have the added disadvantage of language barriers or lack of understanding of how the society works.

HIV/AIDS in South Asian Communities

As of 2001, 298,372 or 12.0 per cent of our population of the City of Toronto, identify as South Asian. South Asians make up the fastest growing immigrant population in the GTA and, if trends continue, by 2017 are anticipated to be the largest visible minority in Canada.

According to Statistics Canada, between 1996 and 2001, people who reported South Asian origin rose by 33%, while the overall population grew by only 4%.

It is difficult to estimate how many South Asians in the Toronto area are living with HIV. Given the World Health Organization (WHO) prevalence rate of 0.19% for Canada, it can be estimated that approximately 566 South Asians may be infected with HIV in the Toronto area.

Discussions with people living with HIV/AIDS and Key Informants characterize life within the South Asian communities as follows:

HIV/AIDS is not talked about openly within South Asian communities. This is related to social taboos that exist within the communities. Some examples of prevailing ideas are:

- South Asians are monogamous.
- Women do not get HIV/AIDS unless they are promiscuous.
- South Asians do not use injection drugs.
- If you talk about something bad (like HIV/AIDS) it will happen.

While these prevailing ideas are clearly not true, they reflect the dominant values and beliefs held by many within the communities. Together, they contribute to a silence within South Asian communities that leads to denial that HIV/AIDS is a South Asian disease. The only socially acceptable way to talk about being ill with HIV/AIDS is to couch it in terms of a blood transfusion as the cause or using another diagnosis like cancer.

People fear being mistreated, abandoned or isolated if they tell other South Asians about their status. They fear that if they disclose, no one will be their friend, come to their homes, eat their food, or play with their children. Because of the taboo and fear, it is not uncommon to find partners who do not know their loved one's status for quite some time after a positive HIV diagnosis is received. Because of the collective culture that typifies South Asian communities, people who disclose stand to not only lose

the support of their immediate family/friends, but also their relationship with their entire community. If they are relatively new to Canada, or have been here for some time but do not speak English, or have few connections outside of their South Asian community, then the loss is even more acute and far reaching.

Faith is a central part of many South Asians' life and has strong links to their cultural life as well. Faith communities are often the guardians of the prevailing ideas that contribute to the silence in the first place. They are seen as very powerful vehicles for carrying messages related to social, cultural and spiritual matters. Therefore, most people living with HIV/AIDS do not reveal this information to members of their faith community, even though many would wish to. For some who have revealed the situation to their faith leader, the response has been supportive.

Taboos that exist within the South Asian context are more rigidly applied to women. There is a greater emphasis on the role of women to protect the family name and reputation. For some women, this makes the disclosure of a positive HIV status harder. They do not want to be held responsible for their family's bad name. They also need to consider their ability to provide for their children on their own if they are ostracized. On the other hand, however, because women are socialized in their role as caregivers/nurturers, they are sometimes more likely to disclose and seek support in order to best fulfill this role for their children and the family.

There is limited experience within the South Asian Organizational (SAO) infrastructure with the range of issues related to HIV/AIDS. Staff often lack awareness and sensitivity or are not comfortable with the issues, have many of the same fears and misconceptions about transmission as the general public, and do not know where to refer people who are HIV positive for specialized services.

South Asian physicians play a central role in the lives of many in the community but no South Asian doctors with an HIV designated practice were identified by project participants. This means that South Asians living with HIV/AIDS must get medical attention outside their community.

South Asian people who are HIV positive often go outside of the South Asian communities for their initial testing, bringing them into contact with mainstream AIDS Service Organizations (ASOs). This is partly because of fear and shame but also because South Asian doctors refer people to specialists like Hassle Free Clinic for testing. As a result, many South Asians are often more likely to first disclose or discuss their status with someone outside their community, particularly someone affiliated with an ASO. There are varying reports about how satisfactory this experience has been.

Mainstream ASOs are generally not perceived to be reflective of South Asian communities culturally, linguistically or from a faith perspective. ASOs are perceived by many to be "white gay man friendly". Therefore, many South Asians may not be able to identify with most people involved with the mainstream ASOs because of cultural or racial issues or because they do not consider themselves gay.

Specific examples of mistreatment and discrimination are cited within the areas of health care, welfare, the financial and insurance industry, employment, housing, immigration, travel and the law. However, it is hard to understand the degree to which individuals experience discrimination related to HIV/AIDS because of the silence about it

within communities and the everyday racism people in the South Asian communities encounter.

The overall findings reported in this study demonstrate that South Asian people living with HIV/AIDS experience **felt stigma** within a silent community that basically denies that HIV/AIDS is a South Asian problem or issue. They also experience everyday racism living in Canada. They have to cope with two kinds of discrimination – felt stigma and racism. Individual's lives are compromised beyond just the HIV/AIDS illness.

The larger implication of these findings is that South Asian communities that are already vulnerable to racism and marginalization within the broader Canadian context are also at risk for the spread of HIV/AIDS. The denial, ignorance, stigma and silence are all conditions for people to continue to engage in high-risk behaviour, and for community education strategies to be rendered ineffective. Overall, this could contribute to the proliferation of a disease that should be controllable.

The pervasive silence on the issue of HIV/AIDS must be broken. There is a pressing need to reduce the silence and stigma around HIV/AIDS, and to create an environment where disclosure is more the accepted norm.



K. Recommended Resources

FILMS

The Age of AIDS, produced by Frontline, PBS (2006)

- This amazing documentary initially aired on PBS and provides a clear and comprehensive explanation of the history of HIV/AIDS and the stigmas that have persisted historically and to the present day. The accompanying website provides a wealth of information and access to the film itself:
www.pbs.org/wgbh/pages/frontline/aids

After Stonewall, directed by John Scagliotti (1999)

- An excellent documentary and comprehensive look at the significance of Stonewall and the galvanizing of America's LGBTQ community, including the advent of AIDS.

Track Two, directed by Harry Sutherland. (1982)

- A documentary about Toronto's Bath House Raids and an excellent resource for understanding Toronto's political climate and activism within the LGBTQ community around the time of the play. It is available to view online for free at www.youtube.com/watch?v=iN4_8eurids.

Outrage, directed by Kirby Dick (2009)

- A powerful documentary about closeted gay politicians in America with staunchly anti-gay voting records. The film tracks this trend in US politics and includes details about Mayor Ed Koch and his response to the gay community and the early days of AIDS. It includes great Larry Kramer footage and fascinating interviews with Rodger McFarlane (the real-life "Tommy" from *The Normal Heart*).

Gay Sex in the 70s, directed by Joseph Lovett (2005)

- This documentary is an excellent resource for understanding the sexual politics and context of *The Normal Heart*. **Please note that the film includes sexually explicit scenes and imagery that may not be appropriate for young audiences.** You may choose to screen selected excerpts for your students.

Sex Positive, directed by Daryl Wein (2008)

- A documentary about lesser-known activist Richard Berkowitz, the film provides more background regarding sexual politics of the 70s and 80s and the debate about safer sex within the gay community with the advent of AIDS. **Please note that the film includes sexually explicit scenes and imagery that may not be appropriate for young audiences.** You may choose to screen selected excerpts for your students.

And the Band Played On, directed by Roger Spottiswoode (1993)

- This HBO made-for-TV movie about the early years of AIDS was a controversial film when it first aired. Based on the book of the same name by Randy Shilts, this narrative feature provides an overview of AIDS in America with a focus on the CDC and medical community.

BOOKS

AIDS Activist: Michael Lynch and the Politics of Community, by Ann Silversides
(Toronto: Between the Lines, 2003)

- We highly recommend this wonderful book about the history of AIDS activism and community organization in Canada for all teachers and students interested in learning about HIV/AIDS in a local context.

COMMUNITY ORGANIZATIONS AND WEBSITES

AIDS Committee of Toronto (ACT)

www.actoronto.org

Toronto People With AIDS Foundation (PWA)

www.pwatoronto.org

AIDS Action Now! (AAN!)

www.aidsactionnow.org

Gay Men's Health Crisis (GMHC)

www.gmhc.org

AIDS Coalition to Unleash Power (ACT UP)

www.actupny.org

Community AIDS Treatment Information Exchange (CATIE)

www.catie.ca

HIV & AIDS Legal Clinic (Ontario) (HALCO)

www.halco.org

Black Coalition for AIDS Prevention (Black CAP)

www.black-cap.com

Alliance for South Asian AIDS Prevention (ASAAP)

www.asaap.ca

Ontario Aboriginal HIV/AIDS Strategy (OAHAS)

www.oahas.org

Asian Community AIDS Service (ACAS)

www.acastoronto.tumblr.com

Prisoners' HIV/AIDS Support Action Network (PASAN)

www.pasan.org

Pride Toronto

www.pridetoronto.com

The 519 Church St. Community Centre

www.the519.org

LGBT Youth Line

www.youthline.ca

Toronto Public Health

www.toronto.ca/health

British Columbia Centre for Disease Control

www.bccdc.ca

Insite Supervised Injection Site

www.supervisedinjection.vch.ca

Appendix A. First New York Times AIDS Article

RARE CANCER SEEN IN 41 HOMOSEXUALS

by LAWRENCE K. ALTMAN

THE NEW YORK TIMES

Published July 3, 1981

Doctors in New York and California have diagnosed among homosexual men 41 cases of a rare and often rapidly fatal form of cancer. Eight of the victims died less than 24 months after the diagnosis was made.

The cause of the outbreak is unknown, and there is as yet no evidence of contagion. But the doctors who have made the diagnoses, mostly in New York City and the San Francisco Bay area, are alerting other physicians who treat large numbers of homosexual men to the problem in an effort to help identify more cases and to reduce the delay in offering chemotherapy treatment.

The sudden appearance of the cancer, called Kaposi's Sarcoma, has prompted a medical investigation that experts say could have as much scientific as public health importance because of what it may teach about determining the causes of more common types of cancer.

First Appears in Spots

Doctors have been taught in the past that the cancer usually appeared first in spots on the legs and that the disease took a slow course of up to 10 years. But these recent cases have shown that it appears in one or more violet-colored spots anywhere on the body. The spots generally do not itch or cause other symptoms, often can be mistaken for bruises, sometimes appear as lumps and can turn brown after a period of time. The cancer often causes swollen lymph glands, and then kills by spreading throughout the body.

Doctors investigating the outbreak believe that many cases have gone undetected because of the rarity of the condition and the difficulty even dermatologists may have in diagnosing it.

In a letter alerting other physicians to the problem, Dr. Alvin E. Friedman-Kien of New York University Medical Center, one of the investigators, described the appearance of the outbreak as "rather devastating."

Dr. Friedman-Kien said in an interview yesterday that he knew of 41 cases collated in the last five weeks, with the cases themselves dating to the past 30 months. The Federal Centers for Disease Control in Atlanta is expected to publish the first description of the outbreak in its weekly report today, according to a spokesman, Dr. James Curran. The report notes 26 of the cases – 20 in New York and six in California.

There is no national registry of cancer victims, but the nationwide incidence of Kaposi's Sarcoma in the past had been estimated by the Centers for Disease Control to be less than six-one-hundredths of a case per 100,000 people annually, or about two cases in every three million people. However, the disease accounts for up to 9 percent of all

cancers in a belt across equatorial Africa, where it commonly affects children and young adults.

In the United States, it has primarily affected men older than 50 years. But in the recent cases, doctors at nine medical centers in New York and seven hospitals in California have been diagnosing the condition among younger men, all of whom said in the course of standard diagnostic interviews that they were homosexual. Although the ages of the patients have ranged from 26 to 51 years, many have been under 40, with the mean at 39.

Nine of the 41 cases known to Dr. Friedman-Kien were diagnosed in California, and several of those victims reported that they had been in New York in the period preceding the diagnosis. Dr. Friedman-Kien said that his colleagues were checking on reports of two victims diagnosed in Copenhagen, one of whom had visited New York.

Viral Infections Indicated

No one medical investigator has yet interviewed all the victims, Dr. Curran said. According to Dr. Friedman-Kien, the reporting doctors said that most cases had involved homosexual men who have had multiple and frequent sexual encounters with different partners, as many as 10 sexual encounters each night up to four times a week.

Many of the patients have also been treated for viral infections such as herpes, cytomegalovirus and hepatitis B as well as parasitic infections such as amebiasis and giardiasis. Many patients also reported that they had used drugs such as amyl nitrite and LSD to heighten sexual pleasure.

Cancer is not believed to be contagious, but conditions that might precipitate it, such as particular viruses or environmental factors, might account for an outbreak among a single group.

The medical investigators say some indirect evidence actually points away from contagion as a cause. None of the patients knew each other, although the theoretical possibility that some may have had sexual contact with a person with Kaposi's Sarcoma at some point in the past could not be excluded, Dr. Friedman-Kien said.

Dr. Curran said there was no apparent danger to nonhomosexuals from contagion. "The best evidence against contagion," he said, "is that no cases have been reported to date outside the homosexual community or in women."

Dr. Friedman-Kien said he had tested nine of the victims and found severe defects in their immunological systems. The patients had serious malfunctions of two types of cells called T and B cell lymphocytes, which have important roles in fighting infections and cancer.

But Dr. Friedman-Kien emphasized that the researchers did not know whether the immunological defects were the underlying problem or had developed secondarily to the infections or drug use.

The research team is testing various hypotheses, one of which is a possible link between past infection with cytomegalovirus and development of Kaposi's Sarcoma.

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Appendix B. Mayor Rob Ford and Pride Week

ARTICLE 1:

Toronto mayor's snub of Pride Week gives bigots cover to spew their bile

by **MARCUS GEE**

GLOBE AND MAIL

Published Wednesday, June 29, 2011 7:42PM EDT

Mayor Rob Ford's unofficial boycott of Pride Week is having a disturbing and predictable effect. It is emboldening the city's haters. Since he announced he would be skipping the Pride parade to go to the cottage, they have been scurrying into the open like insects from an upturned rock, cheering the mayor for staying away from the "disgusting" spectacle on Yonge Street and jeering leaders of the gay community for urging him to attend.

"I'm so glad that Toronto has a mayor who can ignore that vulgar and obscene event," said one comment on The Globe and Mail's online edition. "I think being gay or lesbian is a disease," a Globe reader said in an e-mail. "The queers have to be flamboyant and in your face, just to prove they are 'normal,'" wrote a contributor to another newspaper's comment page. Editors were kept busy deleting many far worse remarks from their web sites.

No one is saying the mayor deliberately whipped up these ugly sentiments, much less that he shares them. But he should have foreseen the damage his snub of Pride could do. Homophobia is an ancient prejudice, still virulent despite the remarkable advances in gay rights of the past few decades. The events of the past week show how swiftly it can resurface.

Glen Brown, the interim executive director of Pride, calls the homophobic remarks "alarming and disturbing," a reminder that gays and lesbians are still a long way from achieving full comfort and acceptance. Only months ago, he says, someone he knows was the victim of a gay bashing near Church and Wellesley streets.

That is why it is so important for public officials to support Pride. When they participate in the Pride parade, as mayors have for more than a decade, they are sending a powerful message that homophobia is not tolerated in our city. They are signaling that the whole city, led by its highest official, stands shoulder to shoulder against this poisonous form of hatred.

By boycotting Pride, declining to attend not just the parade but all other Pride events so far, Mr. Ford is sending the opposite message. He is saying that shunning the gay community is acceptable. He is giving the bigots cover to voice their dark resentments. In effect, if not in intent, he is legitimizing hate.

Mr. Ford's defenders say people are making too much of his absence from Pride. It's just not his thing, so let him be. But gestures like this matter. Imagine how it feels for the gay teenager who is considering coming out of the closet when he hears that the mayor is staying away from Pride and that a good part of the city is applauding him for it.

The mayor's own excuses for staying away are looking weaker and weaker. He said he was skipping Sunday's parade to go to the family cottage for a traditional get-together. But that doesn't explain why he opted out of the many other, more low-key Pride events that have been taking place all this week.

He could easily have defused the controversy and silenced the bigots by walking a few steps from his office to attend the raising of the rainbow Pride flag at city hall on Monday. Instead, he skipped it for a "very important meeting" with Leafs general manager Brian Burke that happened to include a tour of the Air Canada Centre, a bonus for the sports-loving mayor. Mr. Ford came back proudly wearing a new Leafs jersey.

Prejudice is a mob phenomenon. If the mob senses the momentum is going its way, it will run riot. If bigots get the feeling, right or wrong, that the mayor himself is somehow on their side, they will think they have permission to spread their bile. The mayor seems altogether oblivious to the danger he is inviting.



ARTICLE 2:

Mayor Ford mocked but not missed at Pride parade

by **DANIEL DALE**, Urban Affairs Reporter

TORONTO STAR

Published: Sunday, July 3, 2011

Marvin Galvez carried the day's prevailing sentiment on a handwritten sign he held high as he marched down Yonge St.: "Hope you have fun at the cottage Ford! We don't need you!"

Mayor Rob Ford rejected Sunday's Pride parade in favour of a Muskoka weekend. Parade revellers rejected him back – some with the bitterness of a spurned suitor, but many with the carefree air of a day on the dock.

They thought he should have marched. They were insulted he didn't. But they weren't going to let him distract them from the cheering and dancing and ogling and water-gun-squirting that dominated a largely joyous celebration.

"I wouldn't have talked to him anyway. I don't care," said Linda Day, 38, with a smile.

"Screw 'em. He's missing a lot of fun. To his everlasting shame," said Philip King, 51.

"It's kind of irritating, but there's so much other support from other people. We know we're loved here in Toronto. Seeing everyone else kind of reaffirms that we're not alone, and he's not going to have the last word," De Morris, 24.

Fifteen councillors marched – a record, according to Councillor Kristyn Wong-Tam. But almost all of them were members of council's left-leaning minority. Of Ford's allies, only Michael Thompson, Cesar Palacio and Gary Crawford were spotted.

Thompson, marching in his sixth Pride, said Ford's absence from the entirety of the 10-day festival was solely because of his hectic schedule. "I think we need to cut him some

slack. I don't think we ought to castigate, or suggest that the reason why he was unable to attend has any significance," he said.

Ford said he had to miss the parade because of a family gathering at his cottage. A *Star* reporter did not spot him there over three hours Sunday afternoon; when she approached as the family packed up their cars around 5:45 p.m., his niece Krista, daughter of Councillor Doug Ford, said he had gone to Huntsville. She guessed that he was shopping for groceries.

Ford decided to avoid the parade despite a two-week lobbying effort that involved a plea from Maple Leafs general manager Brian Burke, whose late son Brendan was gay. A weary Burke marched in the parade, wearing a jersey with his son's name on the back, less than three hours after a 25-hour journey back from Kandahar, where he spent Canada Day with soldiers.

Ford's absence "didn't really come up," said Wong-Tam. "Every now and again, someone would shout in our direction, 'Where is the mayor?' and 'Shame.' But it was so celebratory, and the energy was electric, and the vibe was so upbeat."

The mayor was not completely ignored. Dozens of marchers and watchers brought an unflattering photo of his disembodied head. At least a few used it as a mask; at least one affixed it to his rear end; Alex Herd, the 67-year-old "second-oldest drag queen in our community," held one on which "someone" had decorated Ford's lips with lipstick.

Marchers affiliated with Ryerson University's student union and RyePRIDE group held a banner that read "We Found Waldo ... But Where's Rob Ford?" They marched in front of a truck decorated with drawings of both.

And perhaps the parade's biggest Ford-related hit was Jon Mandrozos, who wore a large false belly and a giant Ford-ish Styrofoam mask he spent eight hours creating.

At least one police officer burst into laughter upon seeing him.



Suggestions for Discussion Questions:

- What comparisons can you draw between the Mayor in *The Normal Heart* and Toronto's Mayor Ford?
- Is it the Mayor's responsibility to actively support the city's LGBTQ community? Why or why not? Is this responsibility different from that of supporting other communities in the city (eg. Black, Asian, or Muslim communities)?
- How does Globe and Mail journalist Marcus Gee suggest the Mayor's lack of support for Pride trickles down to impact attitudes towards LGBTQ Torontonians within the community at large? What do you think of his argument?

Appendix C. Gay-Straight Alliances in Schools

ARTICLE 1:

Mississauga students to march for gay-straight alliance at Pride parade

by **CHANTAIE ALLICK**

GLOBE AND MAIL UPDATE

Published: Wednesday, June 29, 2011 4:14PM EDT

Catholic students in the GTA are bringing attention to their efforts to create more safe spaces in their schools by marching in Sunday's Pride Parade.

Leanne Iskander is the spokesperson for a group of students at St. Joseph's Catholic Secondary School in Mississauga who have started an "unofficial" gay-straight alliance at their school called the Open Arms club.

The group was in the news earlier this month when the Dufferin-Peel Catholic board prevented the use of a rainbow flag, a symbol of gay pride, at an anti-homophobia event after refusing to allow a chartered gay-straight alliance at St. Joseph's.

"Pride is an excellent way to get the message across to the community, the government, and the Catholic School system that there is a want and a need for gay-straight alliances in Catholic Schools," Ms. Iskander wrote in a news release.

The students are in the process of beginning a coalition of Catholic Students for GSAs and hope their participation in the march will bring more attention to the cause.

Bruce Campbell, a spokesperson for the Dufferin-Peel Catholic School Board, explained that the board supports the students in terms of the need to promote anti-bullying and anti-homophobia efforts, but that any club or group within the board also needs to be in line with the requirements of the Catholic faith.

He said Open Arms "has been widely accepted and hugely successful in terms of engaging students and creating awareness of issues." The board supports anti-bullying and anti-homophobia efforts and see the group as a template that could be used at other schools should there be a demand for it.

Gay-straight alliances are often places to go for support in a school environment, explained Ms. Iskander. "The LGBT students have never had a voice before in Catholic schools. They've been closeted."

Equality For Gays and Lesbians Everywhere (Egale) is an LGBT advocacy group that has been working with Ms. Iskander's club for the past three months. Egale runs a website that provides materials for students who want to establish gay-straight alliances in their schools called mygsa.ca.

There are efforts like the one at St. Joseph's being made by students across the country to develop safe spaces in their schools. "I don't think this is an isolated incident. We're a national organization and we see this right across the country and it's not, unfortunately, specific to the Catholic school board," said Helen Kennedy, Egale's executive director.

This is not just a gay issue either. It affects the school environment in its totality, said Ms. Kennedy. Eighty per cent of students targeted by homophobic violence identify as straight. Egale just completed a study that found schools that have GSAs among their school clubs are safer and the incidence of homophobic violence in schools are reduced because of them.

The benefits of the unofficial GSA at St. Joseph's have already become clear. Ms. Iskander said there has been less bullying in her school because of the club. "If something happens to one of us, there are 50 other people in our GSA who are going to stand up for us." Half the students in the group identify as LGBT.

Ms. Kennedy said she expects the students will have strong support for their efforts on Sunday both within the LGBT community and outside of it.



ARTICLE 2:

Still no name for Catholic clubs against homophobia

by **LOISE BROWN, Education Reporter**

TORONTO STAR

August 19, 2011

Can they use the word "gay?" Are rainbows okay?

Two weeks before classes begin, Ontario Catholic schools still don't know what to call the anti-homophobia clubs they now must allow, because an advisory group has been too torn on the issue this summer to agree on guidelines.

A provincial committee of about a dozen students, parents, teachers, trustees, and clergy has been trying since May to hammer out a "framework" for clubs for victims of bullying because of sexual orientation – but has been unable to agree in time for September because of the range of views among Catholics themselves, said the head of the Ontario Catholic School Trustees' Association.

"It's been a struggle; we want to have groups to help these students so they don't feel suicide is the only option – suicide rates among homosexual young people are higher – but some people get caught up worrying that we're going to forget about our Gospel teachings, and cause panic, so it's taking longer than expected," said association president Nancy Kirby.

The committee has been trying to strike a balance between the Vatican's stand against the homosexual act, and its acceptance of all people, including homosexuals, as children of God. Some parents at a number of Catholic school boards have said they fear anti-homophobia clubs could lead Catholic schools to promote homosexuality.

But Kirby said this is not the case.

"These are definitely not meant to be political action groups, and Catholic schools already teach students that the church does not approve of premarital sex of any kind;

heterosexual or homosexual,” said Kirby. “But the Catholic church also teaches that we love each other and treat each other with respect, no matter your sexual orientation.”

It’s a political balancing act that reflects growing tension between a public school system that requires anti-homophobia measures, and its publicly funded Catholic system that follows the teachings of the Catholic church.

Some Catholic schools in the Greater Toronto area came under fire last spring for refusing to allow students to create clubs with “gay” or “rainbow” in their name for fear it strayed from the church stand against gay sex.

But Catholic students persuaded both trustees and the clergy that such clubs are needed to support students suffering from bullying because they are gay, said Kirby. As a result, the Catholic trustees’ association and the Assembly of Catholic Bishops of Ontario told Catholic schools in April they must let students form groups to support victims of homophobic bullying, but stopped short of allowing the name “gay-straight alliances” or “rainbow clubs.” Instead, they struck a committee to draft the blueprint for these groups – including their name – by the fall, but Kirby said that timeline may have been a bit ambitious for such a complex task.

The trustees’ association sent a memo this week to all Catholic school boards reminding them to let students start such clubs as long as they don’t contradict Catholic teachings, and noting what these clubs should be called or how they will operate will come later this fall.



Suggestions for Discussion Questions:

- Does your school have a Gay-Straight Alliance (“GSA”)? If so, what impact do you think it has on both LGBTQ and “straight” students?
- Do you think having a GSA in the school curbs homophobic bullying? Do you think GSAs make schools more open, welcoming places for all students?
- If you were an LGBTQ student, how do you imagine a GSA would impact your life? *Role-playing and improvisation exercises will help students explore this question.*
- How can faith-based schools such as Catholic schools balance a commitment to religious doctrine with their responsibility to protect the rights and freedoms of their students (including their LGBTQ students)?
- Does language matter? Is it important to name an anti-homophobia club a “Gay-Straight Alliance”? Can clubs be as effective using different language/labels?
- How significant are symbols such as the rainbow flag? What message would the Catholic Board be sending by permitting the use of such a symbol in its schools?
- Toronto’s Catholic School Board is publicly funded. Does this impact the Board’s responsibility to its LGBTQ students? Would Catholic schools have less of a responsibility to permit GSAs if they were privately funded? Why or why not?

Appendix D. Toronto's AIDS Funding

SAMPLE 1:

Ford votes alone against funding for HIV/AIDS programs

By ANDREA HOUSTON

XTRA: CANADA'S GAY AND LESBIAN NEWS

Saturday, July 16, 2011

Once again, Mayor Rob Ford was the lone member on city council to vote against grant money earmarked for HIV/AIDS-related programs.

The grant was even supported by rightwing councillors Doug Ford, Doug Holyday and Michael Thompson.

But not the mayor. In a stunning 37 to one vote at the very end of the day on July 13, Ford said no to budgeted funding for the AIDS Prevention Community Investment Program (APCIP), a program that reaches more than 250,000 people through outreach and workshops.

Councillors who were absent from the vote include Paul Ainslie, Maria Augimeri, Josh Colle, Gary Crawford, Glenn De Baeremaeker, Giorgio Mammoliti and Karen Stintz.

The APCIP allocation was for \$1,679,000, to be used between July 1, 2011, and June 30, 2012.

The funding pays for outreach workers and funds projects at several vital community organizations, including at the 519 Church Street Community Centre, Action Positive, Africans in Partnership Against AIDS, the AIDS Committee of Toronto, the Alliance of South Asian AIDS Prevention, the Black Coalition for AIDS Prevention, Central Toronto Community Health Centers, Fife House, the Hassle Free Clinic, Native Child and Family Services, Youthlink and Schools Without Borders, to name a few.

Black CAP's chair, Angela Robertson, tells *Xtra* that the grants support a community of people who are often marginalized and face tremendous stigma and discrimination.

"The kinds of services that the mayor has voted against are part of invisible yet essential services in our communities," she says. "We need the support of the city for prevention work that these grants support. It's incomprehensible why the mayor would vote against these kinds of supports. But it's heartening to know that these grants were approved."

The projects target gay and bisexual men, injection drug users, women and men from countries where HIV is endemic, people living with HIV/AIDS, gay youth, trans populations, at-risk youth, sex workers and incarcerated men and women.

There is no financial impact beyond what has been approved in the city's 2011 approved operating budget, the city report states.

The vote capped two days at council that saw Ford vote against six other community development grants programs that improve the lives of the city's seniors, immigrants, the poor and the disabled. The community development and recreation committee recommended that the city give 259 groups a total of \$7.2 million. Some of the groups

include Etobicoke Services for Seniors, Cabbagetown Youth Centre, the New Canadian Community Centre and Variety Village.

The mayor was defeated 43 to one when he tried to halt funding for Access Equity and Human Rights, the Community Recreation Investment Program, the Community Safety Investment Program, and Community Festivals and Special Events Investment Program.

Much like his days as a city councillor, Ford made a point of telling city council he opposes them all. Ultimately, all the grants passed.

If he had got his way, the move would have further affected marginalized black communities that are targeted through outreach, Black CAP's Michael Went points out.

"That's funding that helps marginalized black communities. After the vote, he then goes out to celebrate the launch of Caribana."

It's not the first time Ford has voted against funding earmarked for HIV prevention strategies. In February, the mayor was the only member of council to vote against accepting \$100,000 from the provincial government to establish screening programs for syphilis and HIV.

Ford has consistently voted against the APCIP every year since 2006.



SAMPLE 2:

AIDS ACTION NOW! City Hall Deputation Letter

By ALEX MCCLELLAND

July 28 2011

Dear Rob Ford and the Executive Committee,

We are concerned that the recent KPMG report suggests that the Community Partnership and Investment Program (CPIP) and the AIDS and drug prevention grants associated with it are not an essential part of the City of Toronto. As a person living with HIV and as a representative of a group of residents of Toronto who are concerned about issues related to HIV, Hepatitis C, and the health and wellbeing of marginalized groups, we want to make sure you and the Executive Committee understand that to us, these grants are an essential part of life in Toronto for thousands of people.

There are currently over 17,000 people with HIV living as residents in Toronto. Many people who have HIV also have Hepatitis C. These people come from all different walks of life, they pay taxes, vote, live in the suburbs and downtown, and invest in this city. Many are from disadvantaged and marginalized populations and face a great deal of difficulties. This makes life for them, their families and their children, uncertain. Some of these uncertainties can create the conditions where HIV is more likely to be transmitted onto others. In a recent study, 68% of black HIV-positive women reported going without medical care because they could not afford it. The services that provide support to these populations are an essential part of support to residents of our city. Investing in the health of people living with HIV and Hepatitis C is a good investment for our city.

If these grants were no longer provided by the city, we would lose not only food programs, programs for women, and newcomers. We would lose proven methods of reducing HIV transmission and other health issues, such as needle exchange programs. Today, July 28, is World Hepatitis Day. We know that 70% of new infections of Hepatitis C, in Canada, are related to injection drug use. Needle exchange programs are a necessity to cost-effectively protect the health of Torontonians and many are currently funded through the Community Partnership and Investment Program (CPIP).

There is a wide range of scientific evidence indicating that needle exchange and other prevention programs are far cheaper than the cost to take care of people who become sick. As the saying goes, “an ounce of prevention is worth a pound of cure.” Studies estimate that an averted HIV infection saves approximately \$150,000 in lifetime medical costs.

These grants are a sound investment in the lives of residents of Toronto and in ensuring government is being fiscally responsible. We call on you today to understand that the CPIP program, the AIDS and drug grants, and the HIV and sexual health services provided by Toronto Public Health are essential to protecting the health of vulnerable people and to Torontonians in general.

During this Toronto-wide service review, we encourage you to make evidence-informed policy decisions that are fiscally sustainable in the long-term. KPMG’s report does not take into account the long-term financial impact of withdrawing these vital grants that support the health and well being of residents of the city that you represent.

HIV and Hepatitis C are on the rise in our city and taking these grants away will dramatically impact the health of our communities, our taxpayers and your voters while costing our city more money in the long-term. You have an opportunity to show innovation, compassion, and fiscal responsibility. Please do the right thing.

With respect,

Alex McClelland
AIDS ACTION NOW!
Steering Committee Member



Suggestions for Discussion Questions:

- After seeing *The Normal Heart* and reading these articles, can you draw any comparisons? Thirty years later, what has changed and what is similar?
- What responsibility do you think the city has to fund AIDS Service Organizations (ASOs) and grants for AIDS education, outreach and treatment programs? Which characters in the play do you agree with on this issue and why?
- Using the Timeline of Events (**Section F** of this Study Guide) as a beginning resource and conducting further research, identify how government funding has helped PHAs over the years. What do you think the impact would be if Toronto City Council were to cut HIV/AIDS funding?

Appendix E. Criminalization of HIV Non-disclosure

SECTION 1:

WHY GUIDELINES?

by ONTARIO WORKING GROUP ON CRIMINAL LAW + HIV EXPOSURE

<http://ontarioaidsnetwork.on.ca/clhe/>

The Background

People living with HIV have a duty under Canadian criminal law to disclose their HIV status to sex partners before having sex that carries a significant risk of HIV transmission. People living with HIV have been charged, convicted and sent to prison when they have not disclosed – even when no one became infected with HIV. The criminal law also applies to other sexually transmitted infections. But with the exception of three cases (involving herpes, Hepatitis B and Hepatitis C), only people living with HIV have been prosecuted. HIV is not easy to transmit. And HIV medications reduce the risk of transmission and have transformed HIV for many people into a chronic manageable illness.

The Problems

Courts have not clearly defined in law what counts as a significant risk of HIV transmission. This has led to an expansive use of the criminal law. HIV-positive people don't know what the criminal law expects of them. Some have been charged and convicted when they practiced safer sex or had only oral sex. Others have been found not guilty. The criminal justice system, including courts, is ill-equipped to address complex social problems like HIV disclosure and HIV prevention. People living with HIV in Canada face stigma and discrimination. HIV disclosure can lead to a loss of privacy, employment, housing, friends and family, and can sometimes lead to violence. Paradoxically, over-reliance on the criminal law might make HIV disclosure more difficult and might hinder HIV prevention efforts. The criminal law and high-profile criminal prosecutions are making it more difficult to support people living with and at risk of HIV infection, many of whom are already socially marginalized. In light of the systemic discrimination Black people of African and Caribbean descent have historically faced in Ontario society and in the criminal justice system, the significant number of prosecutions against Black men is of special concern and requires further examination. The criminal law will not stop the HIV epidemic. No one wants to be infected with HIV. An HIV diagnosis can be devastating, especially for a person who feels he or she has been deceived. People may feel anger, betrayal, grief and a desire for retribution. But criminal charges, trials and convictions are not a "cure" for HIV. Criminalization of HIV non-disclosure in Canada has gone forward without an informed public debate, without clear rules about when it is appropriate to use the criminal law, and without examining the effect of criminal law on HIV care and prevention. While some situations of HIV non-disclosure may warrant prosecution, we view the current expansive use of criminal law with concern.

The Solution

Prosecutorial guidelines are an important part of the solution. Guidelines can help police and Crown Prosecutors handle HIV-related criminal complaints in a fair and non-discriminatory manner. Guidelines can help ensure that cases are informed by current medical and scientific knowledge about HIV and the social contexts of living with HIV.

What is the guideline campaign and who is involved?

While criminal prosecutions may be warranted in some situations of HIV non-disclosure, we view the current expansive use of criminal law with concern. Criminalization of HIV non-disclosure in Canada has gone forward without an informed public debate, without clear rules about when it is appropriate to use the criminal law, and without examining the effect of criminal law on HIV care and prevention. The Guideline Campaign is being organized by the Ontario Working Group on Criminal Law and HIV Exposure. The Working Group is made up of people living with HIV and representatives of over 20 community-based AIDS organizations from across Ontario. We are calling on Ontario's Attorney General to immediately undertake a process to develop prosecutorial guidelines for cases involving allegations of HIV non-disclosure. We are asking fair-minded Ontarians, like you, to sign our Call for Ontario Guidelines for Criminal Prosecutions of HIV Non-disclosure.

When do people have a legal duty to disclose their HIV-positive status to sex partners?

Parliament did not change the Criminal Code to include an HIV/AIDS-specific crime. Canadian courts have created the law about HIV non-disclosure. The Supreme Court of Canada decided in the *Cuerrier* case that the criminal law has a role to play in HIV prevention. It ruled that people living with HIV have a legal duty to disclose their HIV status to sex partners before engaging in sex that carries a significant risk of HIV transmission. So a person who does not disclose his or her HIV status can be convicted of the Criminal Code offence of aggravated sexual assault even when a sex partner does not become infected with HIV. But the Supreme Court did not clearly define the most important part of the legal test: What counts legally as a *significant risk*? As a result, trial court decisions have been confusing and often contradictory.

- Some courts have ruled that sexual intercourse using a condom does not present a legally significant risk of HIV transmission. Others have said it can be. Yet another court has said that to avoid conviction an HIV-positive person must not only wear a condom but also have an undetectable amount of HIV in their blood (also known as undetectable HIV viral load).
- One court convicted a person living with HIV for having oral sex without a condom. Another court found a person not guilty.

Recently, one person has been convicted of murder, and police have laid attempted murder charges.

Is the criminal law being used against people with other infectious diseases, like other sexually transmitted infections, hepatitis, TB, SARS or H1N1?

There are many other infectious diseases that pose a significant risk of serious bodily harm. The Supreme Court decided that the criminal law could be used to address not only the risk of HIV infection but also of other sexually transmitted infections. However, with the exception of three cases (involving herpes, Hepatitis B and Hepatitis C), only people living with HIV have been prosecuted.

Why is the current criminal law a problem for people living with HIV?

Some people living with HIV have expressed serious concerns about using the criminal law against people who allegedly have not disclosed their HIV-positive status to a sex partner.

- People living with HIV in Canada face stigma and discrimination. HIV disclosure can lead to a loss of privacy, employment, housing, friends and family, and sometimes violence. The criminal law does not recognize this reality.
- Courts have not clearly set out the circumstances under which people living with HIV have a legal duty to disclose their HIV-positive status. The law has not defined with certainty what sex acts, under what circumstances, involve a legally significant risk of HIV transmission.
- Vindictive and abusive spouses, lovers and exes have used the criminal law as a way to control people living with HIV. Spouses, lovers and exes have threatened to falsely accuse their HIV-positive partners of not disclosing their HIV status.
- Many court cases involving alleged HIV non-disclosure have been decided based on credibility. Yet it is difficult if not impossible for people to prove that they disclosed their HIV-positive status, or practiced safer sex.
- Black people of African and Caribbean descent have historically faced systemic discrimination in Ontario society and the criminal justice system. Given this context, and the number of Black men who have been prosecuted for alleged HIV non-disclosure, Black men may be significantly affected by these prosecutions.
- Even when a court finds a person not guilty, his or her life may have already been ruined. A photo and private medical information may have been reported in the media. Before a trial takes place he or she has been judged “guilty” in the court of public opinion. And he or she may have spent many months in jail awaiting trial.

What concerns do people working in the field have with using the criminal law to prevent HIV?

Public health staff, community health and social service workers, HIV outreach and prevention workers, mental health professionals and human rights and civil liberties advocates are troubled by the current expansive use of the criminal law. Many people living with or at risk of getting HIV are already socially marginalized. As front-line workers, including people living with HIV, we know that the criminal law is making it more difficult to support people living with HIV. It might also be making it more difficult to prevent new HIV infections.

What role does public health play in preventing HIV?

The Ontario Health Protection and Promotion Act imposes on public health authorities a legal duty to control the spread of certain infectious diseases, including sexually transmitted infections like HIV. It also gives public health authorities the legal powers they need to protect the public’s health. Public health:

- Provides information, counseling, testing, surveillance and partner follow-up for HIV and other sexually transmitted infections.
- Can order a person living with HIV to take action so that he or she does not put another person’s health at risk (known as a section 22 order).
- Can apply to a court to enforce the section 22 order where there is evidence that the person is not following the order

Does it make sense to use public health powers, rather than the criminal law, to prevent the spread of HIV?

If preventing HIV is our ultimate goal, in the vast majority of cases it makes sense to use public health powers rather than the criminal law. If public health authorities are

adequately funded and effectively exercise the full range of their legal powers, we believe that the vast majority of situations involving HIV non-disclosure can be addressed without recourse to the criminal law.

Does it ever make sense to use the criminal law against people living with HIV who fail to disclose their HIV status to sex partners?

Public health authorities in Ontario may require more resources to effectively address difficult situations where people engage in behaviours that pose a risk of HIV transmission to others. Even with adequate resources, there may be rare cases when public health powers may not be effective to prevent someone from knowingly putting a sex partner at risk of HIV infection. After extensive consultation and study, the Joint United Nations Programme on HIV/AIDS (UNAIDS) recognized a limited role for the criminal law, in cases of intentional transmission – where a person knows his or her HIV-positive status, acts with the intention to transmit HIV, and successfully transmits HIV. UNAIDS also takes the position that the criminal law should not be applied where an HIV-positive person took reasonable measures to reduce risk of transmission, such as practicing safer sex through using a condom or other precautions to avoid higher risk acts.

How can we change the situation?

There are two ways to change the criminal law:

- Parliament can amend the Criminal Code by passing a new law. It can take years of advocacy to convince Members of Parliament that a new law is needed. And if an issue is politically contentious or unpopular, the law might never be changed, or a new law might be worse than the old one.
- Courts, through their decisions, can interpret or re-interpret existing Criminal Code offences. In concert with lawyers, we are working on this. But it can take many years to bring about change through the courts.

But there is a way to change not the law itself, but how Ontario police and Crown Counsel use the law. The Attorney General of Ontario can issue *prosecutorial guidelines*.

What are prosecutorial guidelines?

The Attorney General issues prosecutorial guidelines to assist Crown Counsel in making decisions and to promote high standards and consistency in how criminal cases are handled. Crown Counsel, sometimes called Crown Prosecutors, are lawyers responsible for the prosecution of criminal cases. Prosecutorial guidelines are rarely absolute and do not take decision-making responsibility away from Crown Counsel. They provide the overall philosophy, direction and priorities of the Attorney General and set out detailed practice guidance for Crown Counsel. Examples of criminal offences covered by Ontario prosecutorial guidelines include:

- hate crimes and discrimination
- sexual offences
- spouse/partner offences

Ontario's Crown Policy Manual is available at:
www.attorneygeneral.jus.gov.on.ca/english/crim/cpm.

Do prosecutorial guidelines apply to police and courts?

No. However, Crown Counsel play a pivotal role in the criminal justice system. Decisions by Crown Counsel under prosecutorial guidelines can influence the charges that police lay, whether a case goes to court, and how a case is presented in court.

Have other provinces in Canada developed guidelines for HIV-related criminal cases?

Yes. Since 2007 a brief and very limited [Sexually Transmitted Diseases](#) guideline has been in place in British Columbia. It applies to HIV/AIDS and other sexually transmitted infections, but only provides guidance on:

- communicable disease reporting by Crown Counsel to the public health authorities; and
- the process for review and approval of Crown Counsel’s decision to proceed with a charge.

What about other countries?

In 2008, the Crown Prosecution Service (CPS) of England and Wales published legal guidance entitled, [Intentional or Reckless Sexual Transmission of Infection](#). That guidance recognizes that this area of criminal law is “exceptionally complex,” and sets out how prosecutors should deal with cases where there is an allegation that the accused has passed on an infection during consensual sexual activity. The guidance covers issues such as:

- appropriate use of scientific, medical and factual evidence
- safer sex
- interests of complainants and witnesses

How might Ontario prosecutorial guidelines help people living with HIV?

Guidelines might:

- Clarify the circumstances under which prosecution is appropriate and help ensure that people living with HIV will not be prosecuted where there was no real risk of HIV transmission.
- Help ensure that criminal investigations and prosecutions are informed by a complete and accurate understanding of current medical and scientific research about HIV and the risk of HIV transmission, and take into account the social contexts of living with HIV.
- Help ensure that police and Crown Counsel handle HIV-related criminal complaints in a fair and non-discriminatory manner.
- Make clear that the law applies to all sexually transmitted infections, so that HIV is not singled out and stigmatized.

By asking for guidelines aren’t we giving up on the UNAIDS position that criminal law should only be used to punish intentional transmission of HIV?

No. But under existing Canadian law the UNAIDS position is a long-term goal. The Supreme Court, in the *Cuerrier* case, decided that the criminal law of aggravated sexual assault should include HIV non-disclosure cases where there is a significant risk of HIV transmission – not just intentional HIV transmission. We believe that it is vital to take

practical, strategic, concrete steps right now to limit the expansive use of the criminal law. That is why we are asking fair-minded Ontarians, like you, to sign the Call for Ontario Guidelines for Criminal Prosecutions of HIV Non-disclosure.

To download the guidelines, learn more or get involved visit
<http://ontarioaidsnetwork.on.ca/clhe/>



SECTION 2:

Prosecuting for knowingly transmitting HIV is warranted

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About 6 years ago I met a new patient who was told on her 19th birthday that she was HIV infected. She had been in a relationship with a man 8 years older. Although he knew that he was HIV positive, she did not. He had been thoroughly counselled and knew all about HIV transmission.

The patient fell in love with this man. He did not disclose his status. They initially used condoms but after a while he began to cajole her, saying that condoms were unnecessary and that he had no infections, specifically HIV. He lied to her, exploited her affection for him, reassured her and charmed her. She agreed not to use condoms and he infected her.

The patient was devastated and felt that he should be stopped from infecting others in the same fashion. She called the police and public health authorities, but neither responded. About a year later, by chance, she met another young woman who this man had tried to seduce without condoms, lying about his status. Lucky for her, the young woman refused. My patient was furious and again called the police and public health who took her complaints a lot more seriously. The man was charged, his photo splashed in the media to warn other possible victims (and to ensure that they get tested) and he pled guilty. He was sentenced to 4.5 years in jail.

The man's behaviour satisfied the criteria for prosecution set down by even the most ardent opponents of the use of criminal law in HIV-transmission cases. Edwin Cameron, an HIV-positive Justice of the Supreme Court of Appeal in South Africa wrote: "The use of criminal law to address HIV infection is inappropriate except in rare cases in which a person acts with conscious intent to transmit HIV and does so."¹ UNAIDS states that it "... urges governments to limit criminalization to cases of intentional transmission i.e. where a person knows his or her HIV positive status, acts with the intention to transmit HIV, and does in fact transmit it."² The man who infected my patient and tried to infect another woman acted deliberately and maliciously and should be held accountable by the state for his conduct.

Some argue that criminal prosecution will dissuade persons from being tested for HIV and therefore promote HIV transmission by these persons who do not know their status.³

Such speculation is unsupported by a single published study. No informed and reasonable person would decline HIV testing, thus placing themselves at risk of grave illness and death, just because of the publicized prosecution of some HIV-infected individuals accused of unlawfully transmitting the disease to others. It is not one's HIV infection itself that is the subject of prosecution, it is the intentional or reckless transmission of HIV to others.

Spokespersons for AIDS organizations, anxious about the stigma arising from criminal prosecutions, properly object to including HIV-specific provisions in Canada's Criminal Code. However, protecting HIV-positive persons from any criminal consequence of egregious behaviour can only add to such stigma since HIV-infected persons would then be treated differently than anybody else who deliberately hurts others. HIV infection in and of itself should not automatically exempt those who purposefully or recklessly infect others from the full application of criminal law.

The absence of standard prosecutorial criteria for triggering criminal charges in cases of HIV transmission has fed the solipsistic opposition to the appropriate application of criminal law. UNAIDS opposes the prosecution of those who do not know their HIV status. But what about persons at high risk, who have been told that they exhibit the classic physical signs of HIV infection and have been counselled on transmission and prevention? Such persons should not be excused from criminal liability for non-disclosure and deliberate infection of others simply because they have declined HIV testing. Still, it would be outrageous to apply criminal law in the case of an HIV-infected woman about to be raped, for her failure to disclose. Similarly, criminal prosecution would be inappropriate in the more common situation of an HIV-infected woman who risks harm or being killed if she discloses to her male partner. It is time to establish the reasonable threshold of HIV transmission behaviour that should justifiably lead to criminal prosecution.

An HIV-infected colleague familiar with my views, recently chastised me for being dismissive of the "complex realities within which" people with HIV lead their lives. That reality also includes the patient who received an HIV diagnosis on her 19th birthday.

REFERENCES

1. Burris S, Cameron E. The case against criminalization of HIV transmission. *JAMA* 2008;300:578–80.
2. Criminalization of HIV transmission [policy brief]. Geneva (Switzerland): UNAIDS; 2008.
3. Wainberg MA. Criminalizing HIV transmission may be a mistake. *CMAJ* 2009;180:688.

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Suggestions for Discussion Questions:

- What are the arguments against the expansive use of the criminal law with regard to HIV transmission?
- What are some arguments in favour of utilizing the criminal justice system to curb the spread of HIV?
- Do you think the criminal justice system is the best avenue for dealing with HIV transmission? What benefits/challenges does the system have?
- What are the benefits to taking a public health approach to HIV/AIDS rather than a criminalization approach? What are the challenges to a public health approach?
- Why is the issue of **stigmatization** crucial to this debate? If there were no stigma attached to HIV/AIDS, how would the circumstances be different?
Hint: What are some of the fears and risks associated with HIV disclosure?