



NOW WHAT?

The Possibilities of Disclosure

A Guide by HIV Positive People for AIDS Service Organizations and Their Allies

Front Cover Art

Illustration on the front cover by “André.” André was an HIV Positive man who spent many years of his life in prison. During a Positive Leadership Development Institute™ session, André spontaneously rose to his feet and made a speech during which he presented us with a drawing that he had been quietly sketching as he reflected on his PLDI™ experience.

André said that after spending so many years of his life staring at a prison wall, our leadership experience had given him freedom and joy.

André gave his drawing to us as a gift and wrote the following message on the back of his drawing.

“From all my heart to the HIV world and workers. For the best we get out of you.

If I see you again I will love you again as much as I do today.”

André

This book is dedicated to the memory and spirit of André and to all of us who are able to see
beyond our own prison walls.

Thanks



Living, Breathing and Transforming our World

Positive Leadership Development Institute™

Alumni of Positive Leadership Development Institute™

Ontario AIDS Network

Ontario HIV Treatment Network (literature review on disclosure)

The Consultation Steering Group:

Joseph Babcock

David Hoe

Rick Kennedy

Janet Dunbrack

Tara Jewal

Bridget Young

Close to 90 people contributed to this guide. Those who chose to be named are:

Alanna Groleau

Andre Ceranto

Benjamin Ward

Bob Leahy

Brenda Gagnier

Brian R.

Brigitte Charbonneau

Brittany Cameron

Chris White

Colin Johnson

Darren Nickerson

Dave M.

Desiree Kerr

Diane Schots

George Tesseris

Gord Asmus

Grant J. Cobb

Haoua I.

Greg Downer

Henry Maxwell

Henry Luyombya

James Gough

Jasmine Cotnam

Jean Chenier

Jim Maxwell

June Moyo

Keith T. Showers

K.E.S

Kevin Murphy

Kirk Parry

Kyle Vose

L.C

Mercy Saavedra

Neil Burchell

Norm Hitch

O.G.H.

PNM

Priscilla Muzira

Reginald Dennis

Richard Ash

Richard Dalton

Rob Newman

Robert Rankin

Russ Krebs

S.I

Samuel Ernesto Lopez

Skha Mpofu

Steve Gould

Steven Dwayne Bryk

Ted K.

Thomas Newfiebear White

Wayne Amirault

Wayne Bristow

W David McClure

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The Ontario Accord

It has been almost 20 years since the Paris Declaration stated the fundamental rights of people with HIV to self-determination and their centrality in the decision-making processes that affect their lives. Today, in 2013, GIPA, the greater involvement of people with HIV/AIDS, remains a core principle and challenge for AIDS service organizations (ASOs) and other organizations serving people with HIV/AIDS. The GIPA principle is often expressed as GIPA/MIPA to include *the more meaningful involvement of people with HIV/AIDS*. GIPA is always a work in progress -- a continual process of renewing our commitment and ensuring that our practices at all levels of our organizations ensure the engagement, investment and participation of people with HIV/AIDS.

This guidebook about HIV disclosure builds on Ontario AIDS Network commitment to GIPA through its support for the Positive Leadership Development Institute™ and other activities that affirm the principles of GIPA. One of the foundations of OAN's commitment to GIPA is expressed in the Ontario Accord. The Accord was created in 2011 at an OAN-hosted meeting of people with HIV/AIDS (PHAs) and representatives of Ontario AIDS service organizations to create *Living and Serving 3: GIPA engagement guide and framework for Ontario ASOs*.

The Ontario Accord: A statement of solidarity with GIPA/MIPA

We, people living with HIV/AIDS and allies in the community:

- Commit to the greater involvement and meaningful engagement of people living with HIV/AIDS (GIPA/MIPA); GIPA/MIPA puts PHAs at the centre and is grounded in human rights and the dignity of the full human being
- Aim to transform all who live with, work in, and are affected by, HIV/AIDS in Ontario
- Commit to personal and social transformation
- Value community expertise in embracing the challenge for the betterment of society
- Value inclusion over exclusion, a quest for integrity at all times and the embodiment of self-determination
- Promote the evolution of thought, action and collaboration among us and with our allies

Because GIPA/MIPA is about human struggles and aspirations, ethics, empowerment and accountability are its foundation.

What This Guide Is About

This is a guidebook about the many aspects of healthy disclosure and non-disclosure of HIV status by people with HIV/AIDS. The guide was created by people with HIV/AIDS to help AIDS Service Organizations (ASOs) in supporting people with HIV/AIDS who are wondering about disclosure: Why? To whom? When? How?

The guidebook is rooted in the lived experience of PHAs. It grew from a desire by PHAs to create a perspective on disclosure that will help people with HIV and the ASOs that serve and support them. The PHAs who contributed to this guide hope that ASOs will use the guide to deepen their understanding of the disclosure journey and to inform their policy and program development concerning disclosure.

Some of the insights and advice in the guide are expressed as communication from one PHA to another while other advice is framed as a message from PHAs to ASOs. Where the insights shared by PHAs are voiced as PHA to PHA messages, there is much to be gained by the ASO in listening to this voice. As the final chapter on Empowering Warriors asks of ASOs: Listen to PHAs for they are the experts in living with HIV.

Close to 90 alumni of the Positive Leadership Training Institute™ (PLDI™) met in Toronto in March 2013 to brainstorm about disclosure and provide the main themes and content for the guide. It quickly became clear at the meeting that disclosure involves the whole person in all aspects of life, of which sex and criminalization of HIV transmission are just parts of a holistic picture. Disclosure is a lifetime experience and not just an act required by the law in some circumstances.

We as a community have been sitting on disclosure and feeling powerless for some time, especially as criminalisation has taken the spotlight. We finally have pushed back on this together.

Twelve themes emerged from the group's work:

- Why disclose? To whom? What? When? How?
- Disclosure and freedom
- Modelling the way
- Discrimination and oppression
- Stigma: Rejection and acceptance
- Connection: It takes two
- Dating and relationships
- Children and disclosure
- Disclosure to help others
- Cultural competence
- Involuntary disclosure
- Empowering warriors: Respecting PHAs

All of these themes are included in the guide. The material developed by PHAs at the PLDI™ meeting is supplemented by evidence from the research literature on disclosure compiled by the Ontario HIV Treatment Network (OHTN) and information on the legal requirements for disclosure to sexual partners from the Canadian HIV/AIDS Legal Network.

The experience and insights shared at the PLDI™ meeting was organized by a writer and further informed by the Ontario AIDS Network’s PLDI™ alumni, the leadership of member and affiliated organizations within the Ontario AIDS Network and other experts.

For the sake of brevity, people with HIV/AIDS are often referred to as “PHAs” in the text and AIDS service organizations are referred to as “ASOs”. Call-out boxes in italics are direct quotations from PHAs who contributed to this guide.

The focus of this guide is on how AIDS service organizations can understand and support a person’s right to determine when and how to disclose or not. The context, safety, benefits and degree of disclosing are as variable as the lives of people who are HIV positive. The decision is personal. In most sections, the lived experience of PHAs is presented, followed by practical suggestions for ASOs. The section on Modelling the Way summarizes general principles and approaches for ASOs.

The PHAs who shared their insights for this guide pointed out that HIV-negative people can also face questions about disclosure of their status, particularly if they are involved with HIV positive people through relationships, friendships and in the workplace as volunteers or staff. Disclosure can affect everyone.

From the research literature: The impacts and outcomes of HIV disclosure are wide-ranging. Negative outcomes include: rejection, abuse, violence, stigma and discrimination, while positive outcomes include: more high-quality social support, stronger family cohesion and relationships, reductions in anxiety and depression, and improvements in physical health. Most studies found more positive outcomes than negative ones, particularly over the long term. Furthermore, the majority of disclosers have reported little to no regret post-disclosure.

OHTN literature review

AIDS Service Organizations Can Model The Way

AIDS service organizations (ASOs) are crucial partners for PHAs who are facing decisions about disclosure or the outcomes of disclosure. How can AIDS service organizations model healthy disclosure by the way they operate?

“ASOs should have signage: HIV and HepC friendly, just like the rainbow flag .”

“My ASO is NOT OUT about its own HIV status...why should I be?”

“Have T-shirts, slogans and other HIV+ swag.”

First, the ASO has to be in a relationship with the person with HIV/AIDS. Many PHAs point out that entering the door of an ASO for the first time is a BIG step. It may take many tries before a PHA feels able to take that decisive step.

The ASO can make this easier by being clearly welcoming of PHAs in signage, posters, location, etc. An active and accountable commitment to GIPA signals that HIV-positive people are not only welcome, they are meaningfully involved. A diversity of ways to contact the ASO helps (e.g. ASO participation at events in the community, online, by phone).

PHAs are divided on the question of whether an ASO should be “out” about proclaiming its presence in the community, which may signal acceptance and welcoming of PHAs, or whether the ASO should be discreet as a way of protecting the confidentiality of those who enter its doors. This is a policy decision for each ASO that may vary according to the community being served. ASOs that offer services to a mixed or co-infected population may be perceived as less revealing of HIV status for clients seen walking in and out. On the other hand, an HIV supportive atmosphere can be diluted by a varied clientele who may not feel comfortable with each other. Again, this is a policy decision for the ASO.

PHAs offer the following suggestions to ASOs. Some of these may require specialized training of staff and volunteers, working with PHAs and people skilled in counselling:

- Ask PHAs with lived expertise to educate ASO staff and volunteers about the many dimensions of disclosure
- Develop simple language approaches instead of scientific/medical jargon to describe HIV infection; this will help PHAs to have a vocabulary they can use in emotionally charged conversations involving disclosure
- Learn about the complexities of disclosure and how it is linked to self-discovery and overall self-confidence
- Learn about possible approaches to disclosure to another person: how to initiate the conversation, ways to feel the other person out about their readiness to engage in the conversation (e.g. talk about an article or TV program about HIV).
- Focus on keeping the conversation going and the relationship alive even if there is a bad reaction by the other person to a disclosure.

Where Focus Goes, Energy Flows: ASOs can model the way

- Workshops on the many facets of disclosure and how each person's choices are determined by what works for them
- Forums where people can tell personal stories
- Workshops on How to Disclose; include role modelling rehearsals
- Create dialogue about reasons to disclose or not
- Give choice: highlight both the pros and cons around different disclosure scenarios
- Involve HIV negative allies in the disclosure education
- Stigma prevention and education
- Support PHAs to connect outside the ASO to other services as needed (e.g. counselling or legal advice)
- Have HIV positive support workers who can offer peer support
- Partner with other agencies to build capacity to talk about HIV outside the ASO and in the general population
- Provide education for youth including and beyond LGBT (lesbian, gay, bi-sexual and transgender)
- Support the healthy transition of PHA youth and HIV negative youth from youth services to adult health care
- Endorse, adapt and apply the Ontario Accord and GIPA principles
- Continue to evaluate your commitment to the Ontario Accord and GIPA

The following group activity was developed by PHAs to help people experience coming out as HIV positive in a confident way that communicates strength and creates safety where fear existed.

A group experience in a circle:

One person says: *“I am one person and I am HIV positive.”* The next person joins as both say: *“We are two people and we are HIV positive.”* This continues until the entire circle is saying: *“We are N people and we are HIV positive.”*

From the research literature: There have been very few studies examining interventions targeting HIV disclosure. Of the interventions reviewed, those that guided HIV positive individuals through an introspective process, and helped them develop a disclosure plan and the skills to communicate their status, were found to be most effective in increasing disclosure, and improving disclosure outcomes.

OHTN literature review

Why Disclose?

“Disclosure facilitates surrounding yourself with caring, non-judgemental people and weeding out those who aren’t. This is much the same benefit that many GLBT experience after coming out.”

Disclosure of one’s HIV status to other people is a process that starts with the fundamental question: Why disclose? Disclosure must be seen as adding value to life in order for it to be worthwhile;

identifying value makes disclosure easier. PHAs share that reasons for disclosing can include wanting the peace of mind that comes with no longer carrying the burden of a secret or the fear based on anticipation of the other’s reaction to your disclosure. Other reasons can include being honest with yourself and others, which reduces inner stress, raises self-esteem and may allow you to be closer to others. Disclosure can also be a political act, an act of defiance and a deliberate move to change societal stigma.

Freedom can follow disclosure. Many PHAs who disclose either publicly or to a limited number of chosen others describe the freedom from fear and stress which results. Disclosure can also open the possibility of getting support, both practical and emotional. In the sexual context, disclosure can be part of protecting yourself and others.

From the research literature: Negative reactions from family, friends, employers and the community were relatively low, ranging from 3% to 15% of reported disclosures.

OHTN literature review

PHAs who have a long-standing experience with disclosure suggest the following strategies. The ASO can support PHAs in developing these strategies:

- Know whether you are ready to do it: Do you have the required self-acceptance to weather the challenges?
- Understand why you want to disclose and what you expect in return
- Be prepared for the reactions of others – positive and negative; role-playing in advance can help
- Think through the impact that your disclosure may have on you and others you care about – family, children, friends, employers, co-workers – and the degree to which you care about the impact on them
- Choose the best time for you and for the other, preferably when you are both feeling calm
- Ask if you can speak in confidence
- Say where you are coming from and what you are telling them. For example, “I’m HIV positive and I’m telling you because you’re important to me.”

“When I disclose, I feel like a flower: vulnerable and exposed, but powerful.”

In a safe environment where disclosure is possible, there are benefits post-disclosure:

- Less stress in daily life because you are not carrying a secret and don't have to remember what you told to which people
- Feeling empowered and having more choices
- No longer having to keep track of the repertoire of stories about why you:
 - Take all those drugs and vitamins
 - Attend meetings and educational events around HIV/AIDS
 - Do all the self-care things to stay healthy
 - Educate the public about HIV/AIDS
 - Educate your children and grandchildren about safe sex.
 - Educate people about medical marijuana and why it is necessary
 - Help to reduce the stigma about HIV status

Those who have disclosed widely speak about the freedom to choose to step away when others cannot deal with their disclosure. This takes self-confidence and the knowledge that there are others who will support you even when particular individuals don't or can't.

PHAs caution that the fear of disclosing while you are in an unsafe environment is well founded and that you must get to a safer place to disclose and reap the benefits.

Where is a safe place? Some find that AIDS service organizations (ASOs) are, while others find they are not. This depends on a number of factors: whether confidentiality safeguards are in place and are respected, and whether the environment itself is safe. Some PHAs find that an ASO that offers a mix of services and is “too poor” to focus specifically on HIV+ programming may not be a safe place to disclose. An example cited by some PHAs is the mix of harm reduction clients (who may not be HIV+) with HIV positive clients in a multi-service agency: homophobic HIV negative clients may create an unwelcoming atmosphere for PHAs.

A word of advice from PHAs to ASOs: *Value our choices and work with us on making empowered choices. We will make a variety of disclosure decisions - they may seem inconsistent choices but they reflect our complicated lives. The choice is ours to make. Disclosure is always a balancing act that respects both safety and openness.*

From the research literature: Common facilitators/reasons for disclosing are: trust in the recipient of disclosure; positive experiences with previous disclosure; existence of strong social support; to gain social support; to obtain stress relief from withholding a secret; obligation and duty to inform; self-acceptance of HIV positive identity; to share knowledge; and to control disclosure (i.e. to disclose before someone else exposes them).

OHTN literature review

Why Not Disclose?

The other side of the disclosure question is **Why not disclose?** Fear is a major reason: fear of rejection, stigma, discrimination, job loss, and even physical violence. Another reason is the desire to protect others from the distress they may experience when your status is revealed. Many PHAs spoke about having to support the other after disclosing their status.

“ASOs need to provide skills development on disclosure: for PHAs, staff and volunteers.”

“Question the assumption that universal disclosure is a good thing: Disclosure is a personal choice.”

“Give equal value to disclosure and non-disclosure: respect the person’s choice.”

From the research literature: Non-disclosure is often used as a mechanism to achieve a person’s identity goals, which might be to maintain a positive identity and avoid stigma and discrimination. If there are regrets about any disclosure event, they generally fall into six categories: lack of preparation; poor timing; wrong context or setting; unsatisfactory disclosure content; second-hand disclosure; and negative outcomes.

The selective approach to disclosure is most common amongst PHAs. Disclosing is a way of coping, as is not disclosing, and results from the strategic weighing of the benefits and harms of disclosure for each disclosure event. Generally, selective disclosers will only disclose to those individuals who they deem likely to have a positive reaction and would be able to provide support, and to those who they feel the duty to inform (such as medical personnel or sexual and/or drug-using partners).

OHTN literature review

ASOs can support people dealing with the decision not to disclose by helping the PHA work through the reasons for this choice, respecting the choice and supporting the PHA to develop strategies for selective disclosure if that fits with the PHA’s desires and circumstances.

Discrimination and Oppression

There are ways to reduce the risk of discrimination and oppression that can be a consequence of disclosure. Disclosure can be a radical way to break the silence and confront oppression. Disclosure can be an act of seeking and affirming justice.

An important way to combat discrimination is education by role models. Leaders, both HIV-positive and HIV-negative, have to model the way of open, inclusive attitudes and practices. ASOs can support education and the fostering of PHA role models.

People who express hatred or practice discrimination toward PHAs have to be challenged through political action, advocacy, demonstrations and policy development. Legal action through human rights tribunals and the courts may be required. The ASO has a role in advocacy and policy development. It can refer PHAs to other agencies for legal advice if it does not have in-house expertise and it may choose to support a PHA who undertakes legal action against discrimination.

The risks of disclosure can be great and involve loss of:

- Family and friends
- Job and job opportunities
- Security: emotional, physical, financial
- Reality when your world seems to fall apart after disclosure

The basic values that support disclosure can provide strength:

- Each and every human being has value and must be valued
- Accept that life is difficult: Disease is part of life
- Give equal value to the individual PHA's decision to disclose or not to disclose

From the research literature: Common barriers to disclosing are: negative experiences with previous disclosures; fear of discrimination, stigma and rejection; lack of a strong social network; feelings of shame and guilt regarding one's status; struggle with HIV+ identity; cultural factors (i.e. homophobia) within one's community; lack of HIV education and inability to cope with the outcome of the disclosure; and concern of harming or burdening others.

OHTN literature review

Stigma: Rejection and Acceptance

Stigma and fear of stigma create barriers to disclosure. Stigma includes HIV related shame, fear, prejudice, discrimination and guilt. Most ASOs engage in advocacy against stigma and discrimination as part of their mandate. They have a critical role to play in challenging stereotypes in the media and confronting messages that negatively portray or stigmatize HIV-positive people.

Stigma of PHAs leads to negative judgements, misinformation and ultimately, isolation of the person being stigmatized. Rejection can be visible or invisible and may lead to isolation and depression. When a PHA is rejected, internal stigma or shame is reinforced. Some PHAs have experienced becoming tougher and more resilient through facing rejection, but acknowledge that this is a difficult path. Acceptance by the other creates relationship and can lead to enhanced self-esteem by the person being accepted, who feels validated. It all comes down, though, to being able to love yourself because that is the basis of everything. Loving yourself is easier when others accept you.

“Love yourself because that is the basis of everything.”

Some PHAs observe that engagement through their ASO or in other contexts has changed over the past decades. Many see that being a PHA and offering life experience as a job qualification in an ASO is not considered enough and that university degrees and prior work experience count more now. As some PHAs said: *The credentialists are in power*. Some PHAs do not find their local ASO to be a source of support and instead turn to social media and virtual support that is gay positive and/or PHA positive.

From the research literature: Perceived stigma is associated with an individual’s self-acceptance of their disease status and overall perception of self – if they haven’t come to terms with their disease, and feel shameful or guilty, then they would be unlikely to talk about it with others.

OHTN literature review

How can ASOs create environments that feel safe and welcoming for PHAs and that value the expertise of their lived experience with disclosure? Some suggestions from PHAs:

- Identify and support peer champions and mentors; facilitate connection of mentors with PHAs
- Promote existing programs that validate PHAs
- Share stories based on lived experience: success stories inspire and less than successful stories are learning tools that can lead to strategies for better choices and experiences
- Train PHA leaders locally and support their attendance at other opportunities such as the Positive Leadership Development Institute™
- Offer virtual support on the ASO website: information; videos; personal stories
- Form and encourage support groups for disclosure choices; empower PHA group leaders
- Create programs that help PHAs build self-esteem. Learning to love and practise self-care and self-love are important tools for building strength for disclosure choices
- Offer counselling and support to individuals and groups of PHAs who are dealing with disclosure decisions and the results of those decisions. Include crisis support in this program.
- Employ PHA staff
- Do educational outreach about disclosure to health care providers and social service agencies
- Use role playing as a highly effective way of helping PHAs work through their decisions and disclosure encounters

"INCLUSIVITY...RESPECT...Words used by an ASO can make or destroy a person."

Disclosure etiquette advice from THESTIGMAPROJECT

"When a PHA discloses, instead of stigmatizing remarks like: How long do you have? How did you get it? Who gave it to you? Why am I not surprised?"

Empathize and affirm:

"You're not alone. Have you started treatment yet? I'm here for you. Have you found a good doctor? I appreciate you telling me that."

thestigma.org

From the research literature: Trust was the overarching theme and core value for disclosure among people living with HIV (PHAs). The idea and feeling of 'trust' comes into play when deciding to disclose in many ways. For example, individuals might only disclose if they feel that the recipient of disclosure can be trusted to keep the HIV status information private. More importantly, the act of disclosure requires the trust that the HIV-positive person will not be ostracized, criticized, stigmatized, or rejected after the event.

OHTN literature review

Dating and Intimate Relationships

Dating and sex are part of being human and a way we make connections with other people. Because dating and sex are always exploratory and ideally fun, it is important for PHAs to feel as free as possible to get the best out of dating and sex.

Disclosure in intimate relationships opens up vulnerability and requires listening to each other, probably many times over. Disclosure may be done in the hope of making a better life in that relationship for five minutes or for the rest of one's life.

HIV and what it means will be present whether we like it or not. Usually sex can be improved by disclosing simply because that creates the freedom to enjoy, especially with casual sex. With dating, people disclose huge amounts of themselves and HIV is just one of those things; in fact, HIV status may not be the most difficult disclosure.

"In a dating context, you are offering something private by disclosing and it may be a deal breaker. If it is, do you really want to stay with someone who cannot see beyond HIV?"

Even when HIV is not in the picture, dating can be nerve-racking. Many of us fear intimacy because of bad experiences at some stage of our lives. HIV can shake your confidence and make dating/relationships with someone you care about even harder. It can also inhibit communication. Do you disclose? How? When is the best moment?

How can ASOs help? By supporting PHAs to develop strategies for dealing with disclosure in dating and relationships and the challenges described here.

PHAs point out that you have to ask yourself if you are using your HIV positive status as an excuse for anticipated rejection and giving up on the relationship or as an excuse for rejection when other reasons for lack of compatibility may be the cause. It is easy to postpone disclosure: is this a one-night stand (without disclosure) or could it turn into something more? What do you do when you want to see the person again and you haven't disclosed?

The first step in a potential relationship is meeting the other person. The ASO may be a meeting place, or a place to discuss and strategize about how to meet people. Serosorting (meeting others with the same HIV status) has benefits and downsides. A benefit can be less concern about declaring your status. On the other hand, it limits the dating pool and even someone of the same HIV status may be carrying STIs that still require disclosure and/or protection. A relationship between people of the same serostatus will still have to deal with differences of culture, ethnicity, spirituality, sexuality (e.g. same sex or bisexual), temperaments, etc.

The HIV negative partner may have fears after the PHA discloses: fear of HIV transmission, fear of your getting sick or dying, fear of having to be a caregiver, and discomfort by both partners if being serodiscordant creates a power imbalance. There are success stories showing that serodiscordant relationships can work well.

Regardless of serostatus, PHAs report that partners can be surprisingly supportive. Disclosure gets the issue out of the way and out of the fear zone. It also gets the legal issue out in the open and dealt with.

“When you have casual sex before dating the person, later disclosure can become awkward.”

Some PHAs say that early disclosure resulting in rejection weeds out “the bad apples”. When disclosure leads to acceptance, the relationship can be more authentic, based on honesty and trust. In an enduring relationship, the longer you put off disclosing, the harder it can become and the higher the potential for your partner to feel betrayed because you did not disclose earlier or because you did not trust him/her enough to disclose.

Disadvantages of disclosing early in the relationship are “guilt by association” – others may assume that your partner is also positive – and the potential for breaches of confidentiality and involuntary disclosure.

Finally, experienced PHAs say that you don’t have to go as far as a live-in relationship; living alone can be fine.

Disclosure can be difficult when strong feelings and the law are involved. On the emotional side, the person disclosing has to work through how intimate they expect and want the relationship to be. If there is a chance of becoming more deeply involved, disclosure will be on the table at some point. As well as the desire to protect one’s partner, the legal obligation to disclose comes up when the relationship includes sex where the virus can transmit from one person to another. Taking the initiative to disclose can be more appealing than waiting for your date or partner to raise the issue. Reasons for disclosure include the desire to deepen the relationship and establish it on a foundation of honesty.

The reasons for choosing not to disclose can include fear of losing the relationship or the risk of having the other disclose your status through gossip, leaving you to deal with the repercussions of involuntary outing.

Strategies suggested by PHAs include:

- Introduce the topic of serostatus by asking about the other's status or sexual history
- Inform yourself about the legal requirements for disclosure to sexual partners (Links to further information are provided in the Resources section)

From the research literature: In long-term relationships, the disclosure process is an act of honesty and integrity that improves a relationship in healthy situations; however, poor (unsupportive, strained or abusive) relationships are rarely strengthened and often worsened by disclosure. In those situations, disclosure can lead to increased stress and poorer psychological wellbeing.

OHTN literature review

Casual sexual partners: Disclosure in this context is both a health and relationship choice and a legal requirement when it includes sex where the virus can transmit from one person to another. Suggested strategies include:

- The choice about disclosure depends on how and where you meet your sexual partner. For example, if you are seeking partners online, you can include your HIV status in your profile so that you get it off your chest. This does not mean that you have disclosed in the eyes of the law.
- You can disclose in person directly or use an indirect approach to broach the topic, such as asking about sexual practices and preferences

Sex, HIV and the law

There are good resources available about the legal duty to disclose to sexual partners. Links are provided in the Resources section of this guide. Note that these resources provide legal information, not legal advice – you need to consult a lawyer for legal advice and be aware that the law may have changed since this guide was written.

From the Canadian HIV/AIDS Legal Network's analysis* of the 2012 Supreme Court of Canada decision: If there is a realistic possibility that HIV may be transmitted during sex, the HIV-positive person has a legal duty to inform their partner before having sex. The Supreme Court of Canada ruled in 2012, in two cases involving vaginal sex, that the PHA does not have a legal duty to disclose if their viral load is low or undetectable (the Court cited 1500 copies or less of HIV per millilitre of blood as "low" and 50 copies per millilitre of blood as "undetectable") and if they wear a condom. This ruling would likely also apply to anal sex, where the risk of transmission is higher than in vaginal sex. The legal duty to disclose where there is a possibility of HIV transmission through oral sex or needle sharing is unclear.

Caution is needed when deciding that viral load is undetectable. Research has shown that even when viral load is undetectable in blood, it may be detectable in semen, vaginal fluid and rectal fluid.

**Canadian HIV/AIDS Legal Network: HIV non-disclosure and the criminal law: An analysis of two recent decisions of the Supreme Court of Canada (2012).*
www.aidslaw.ca/publications/publicationsdocEN.php?ref=1326

How ASOs can help:

- Learn from PHA experiences such as those described in this guide and incorporate this learning into your organization's policies and programs
- Remember that relationships are more than sex and law. The emotional dimension needs to be acknowledged in your work. Helping people deal with things like relational dynamics and moral distress may fall within your counselling or group support work. If it doesn't, consider creating programs and ensure that you can help PHAs find this support elsewhere if needed.

Other Relationships and Contexts

Disclosure is always done in relationship to others, even when it is done virtually, as on a dating website. Someone somewhere will react to the disclosure. PHA experience of disclosure in several contexts is shared here. Advice from PHAs to ASOs is provided at the end of this section.

From the research literature: Disclosures with a plain, direct and blunt message, such as “I have HIV,” are more likely to elicit negative emotions of sadness and fear. However, a simple message also yielded more emotional support, advice, and a feeling that disclosure made them feel closer to the disclosing individual. Messages that sought support, such as “I am going through a really hard time right now and could use your support. I was recently diagnosed with HIV,” led to higher levels of support and concern, and relatively low levels of blaming.

OHTN literature review

Friends and Family

Disclosing to friends and family may be done in the hope of strengthening relationships and receiving support from them. Disclosure can also be pre-emptive: you may want to disclose to them before someone else does, such as a careless health care provider or a mutual acquaintance. Reasons for caution in disclosure include the possibility of rejection and loss of relationships, and being cut off or ostracized. Family and friends may not be able to understand or accept your situation or be able to cope with their own emotions. There may be conflict with religious, cultural or social roles and values. Disclosure may cause a shift in the roles and responsibilities within your family and social circle.

From the research literature: Literature shows HIV positive people tend to disclose more frequently to family and relatives than to friends, and also to steady/long-term/monogamous partners more often than casual partners, perhaps because of the perceived probability of gaining support and the inherent level of trust. Disclosing to seek support is most likely when the individual perceives a strong social network and is less likely when an individual feels socially isolated.

OHTN literature review

PHAs who have experience with disclosure suggest considering the following strategies:

- Evaluate the nature of the relationship: Is it really necessary to disclose? Why?
- In disclosing, explain to the other that you wish to disclose because you want to become closer to them
- When disclosing, use an evidence-based approach: prepare your information in advance and anticipate the challenges. Have answers to possible questions about HIV/AIDS and be able to dismantle misconceptions. Offer alternate sources of information (e.g. websites, AIDS service organizations, health care providers)
- Prepare yourself for emotionally charged reactions. It can be helpful to mentally walk through possible scenarios or role-play in advance with others you trust.

From the research literature: HIV positive individuals may sometimes disclose their status as a way to reconcile and reconnect with friends and family members, with whom they might have strained relationships due to their sexuality, history with addictions, or any other reason.

OHTN literature review

The Workplace

The decision here may be less emotionally fraught because relationships are more distant than in the personal sphere, but practical considerations weigh heavily. You may want to disclose to your employer if you need special considerations such as time off for medical appointments or periods of ill health. You may be required to reveal your status to join a group benefits plan at work, although by law this information should be confidential and protected. With your co-workers, you may choose to disclose because you have become friends and are faced with the same considerations as with family and friends. You may also wish to explain to them that if you are absent from work, it may not always be HIV related and it is not because of laziness or lack of commitment to your job. The downside of disclosure is the potential for discrimination and gossip resulting in involuntary disclosure.

Suggested strategies:

- If you disclose your status to your employer, do so in writing and request a written response. Keep your letter and your employer's response on file in case of later discrimination.
- Be aware of your legal rights and legislation/law dealing with workplace discrimination; AIDS service organizations may be able to help you become informed.
- Report discrimination by your supervisor or co-workers to upper management and/or the human resources department
- Consider a human rights or Charter challenge if necessary. You may get support for this through an AIDS service organization or legal organization.

From the research literature: The challenge of workplace disclosure is becoming more prevalent as more HIV positive persons are experiencing improved health with the advent of highly active antiretroviral therapy, and are subsequently seeking or maintaining employment. Three studies found that the majority of employed HIV positive persons have not disclosed their status. Those with poorer health, who were visibly ill or had symptomatic AIDS were more likely to have disclosed than those who were healthy.

OHTN literature review

Health Care Providers

The decision to disclose your HIV status to a physician, dentist or other health care worker may be based on your desire to get the best health care possible. Health care providers and settings such as hospitals and clinics are required to use universal precautions which involve protection against contact with bodily fluids for infectious agents such as HIV. The onus is on health care providers in these cases to protect patients and themselves through the practice of universal precautions (e.g. gloves, sterile procedures, etc.). In many cases, your HIV status should not be an issue unless knowledge of your status will help to secure more appropriate and effective care.

“It’s important to have open communication with your doctor and HIV specialist.”

“Most family doctors are learning from us because they do not specialize in HIV but still have to treat you for all health matters. The more they know about your conditions and blood work results, the better treatment you will receive.”

In favour of disclosure is the need to build a network of professionals who are knowledgeable and competent and who will ensure that you get the most successful results from your health care. A further consideration is that drug interactions and duplications can be avoided or minimized when health care providers are aware of your status. On the other hand, the risk of involuntary disclosure increases when more people know your status. The more people who know your status, the less control you have over the information you are willing to provide.

Suggested strategies:

- If you disclose your status, do it in writing and keep a copy
- Make sure that details of your treatment such as viral load reports are documented in your file. This information may be needed if you are in situations with sexual partners where the law does not require disclosure if your viral load is undetectable.

From the research literature: Despite the difficulty disclosure might pose, non-disclosure has detrimental impacts on the person living with HIV and is associated with personal distress, loneliness and social isolation. Furthermore, non-disclosure may lead to medical non-adherence as a way to conceal the disease from others.

OHTN literature review

Going Public

People with HIV/AIDS may want to be completely “out” publicly about their status as a way of raising public awareness, combating stigma and discrimination, and not having to think about HIV status as often. The advantages of being a publicly visible PHA are community minded: it educates other people, normalizes HIV and allows for open dialogue. It may also help the person who goes public to connect with others facing the same challenges while helping those who have not disclosed to connect to someone who understands them. Both the public PHA and non-disclosed PHAs can be empowered. On a personal level, the public PHA may find it easier to disclose face-to-face with significant others because there is nothing to hide. Some mention that they are free of the stress of remembering who knows and who doesn't.

Other benefits experienced by some PHAs include: public speaking and other community work may lead to employment and you gain self-esteem and the knowledge that you are helping others by being a role model.

Those who distance themselves from you after your disclosure are clearly reacting to their own internal realities and you may not know why.

“The friends who stay with you when you are a public PHA are true friends. Those who desert you are not – this is natural selection at work.”

The drawbacks of going public are the risk of discrimination because everyone (personal and work connections) knows your status. Once the information is out there, you have no control over who uses it and how. Some PHAs report that they have been the object of defamation and personal attacks.

Experienced PHAs provide this advice to PHAs who decide to be public about their HIV status:

- Post your status as part of personal information on social media sites
- Discuss your status openly at public gatherings
- Do public education activities that require disclosure; this can include TV appearances and interviews and other media exposure
- Send e-mails to your contacts
- Participate in focus groups, studies, research, support groups and HIV-related events

From the research literature: HIV disclosure is a lifelong process. Reasons for disclosing/not disclosing change constantly - many individuals have their own personal strategies and reasons for disclosing which are carefully planned to elicit positive outcomes. There tend to be fewer disclosures immediately after diagnosis, but the frequency of disclosure as a mechanism to cope with the disease generally increases over time as the HIV positive person gains increased self-acceptance and knowledge of the disease, and increased ability to cope with disclosure.

OHTN literature review

Advice from PHAs to ASOs:

- In your support for PHAs facing disclosure decisions or the consequences of disclosure, include the many dimensions of relationships and contexts in which disclosure can take place
- As always, include in your programs PHA leaders, peers and mentors with experience of the diversity of disclosure situations
- Provide support and/or referral to other agencies that can provide help with things like workplace discrimination or lax confidentiality practices in health care and other settings
- More PHAs are in the workplace. Include outreach to employers and businesses in your community in your education and advocacy work.
- AIDS service organizations must not pressure PHAs to disclose publicly even if they are “out within the agency”. The ASO’s desire to have a visible HIV positive spokesperson for their services does not entitle the ASO to directly ask the PHA to consider public disclosure. The ASO and the PHA need to be aware of, and respect, the power imbalances inherent in this situation. For example, unless there is prior written consent it is not OK for the ASO to ask a PHA to disclose publicly at an event where the media are present and asking to speak with a PHA.
- If employment is offered to a person who is HIV positive, do not assume that the person is out about their status or that they are willing to take on the role of PHA spokesperson either within or outside of the agency.
- Consider different strategies for disclosing PHA participation on Board of Directors such as a percentage of the Board is positive or disclosed designated seats.

Children and Disclosure

Many PHAs are parents – mothers and fathers who may want to tell a child that their parent is HIV-positive or that the child is HIV positive. The wisdom in this section comes from the lived experience of PHA parents and teachers. The ASO may be called on to support parents to work through disclosure to their children; the PHA experience and advice offered here can help inform the organization’s policies and programs. Approaches such as peer support, role playing and counselling can be provided by the ASO to support PHAs who are parents. ASOs can also have educational programs for school personnel and students which inform and de-stigmatize HIV. They can support PHA parents and teachers to be role models and mentors and to speak publicly about HIV and parenting/teaching.

From the research literature: Children report strong negative emotions of shock and fear at the actual disclosure event. Adolescent children have poorer reactions and more problematic adjustment post-disclosure than younger children. Furthermore, there is more reported anxiety among children when the mother is visibly ill at the time of disclosure.

But over time, as children become more informed about the disease and their mother’s health, [Note: this would likely apply to fathers as well] most adjust well and will experience reductions in depression and anxiety, as well as increases in involvement and happiness. Overall, only a very small percentage of children become maladaptive and act out over time – it is important to note that children sworn to secrecy and who have nobody to talk to about their mother’s illness tend to demonstrate more externalizing problems and poorer social competence.

OHTN literature review

PHA parents and teachers offer this advice to those disclosing to children:

- There is only one thing that matters: Is my child safe?
- Know if you are ready to disclose your status and/or the child’s status. Get support in working this through.
- Choose your time carefully. Disclose when you are physically and emotionally able to assist and support the child in adjusting to the news
- Don’t wait for your child to ask questions that lead to your having to disclose or be evasive when you are not prepared
- Identify people the child can turn to for support
- Know and practise the message you want to share
- Seek “teachable moments”; these may be daily opportunities that occur when you are with your child that make it easy to share values and messages.
- Let your child know you are ready to talk with them about sexuality

- Listen to what your child is saying through words and body language to understand their questions and level of awareness/readiness
- Use age appropriate language
- Provide age appropriate materials such as books that have culturally-balanced and medically accurate information
- If you don't know the answer to your child's questions, offer to look them up together (model the way)
- Find out what your child's school is teaching about HIV/AIDS and the school's policies on protection of confidential information. This is a process you will have to go through during all of your child's school years.

From the research literature: Children who are unaware of their mother's HIV status can often perceive something is wrong and thus become distressed when they are unable to express their feelings. Strategies and advice specific for HIV positive mothers planning disclosure to children: [Note: these strategies also apply to fathers]

- Prepare a 'safe list' of people their children can talk to after disclosure to relieve the stress caused by secrecy.
- Make the disclosure personally and do the actual explaining to the child— although another person could be in the room for support.
- Control your emotions and demeanour – stay calm and natural.
- Provide emotional support and reassurance throughout the disclosure process to reassure them and dispel their fears.
- Plan appropriate psychological follow-up for the children to discuss their concerns and fears, and perhaps seek professional support after the disclosure to increase the venues through which the children can address their anxieties.
- Introduce children to other healthy HIV positive mothers so they know they're not the only ones coping with this illness, and they can see other mothers living healthy productive lives.

OHTN literature review

Advice from PHAs to ASOs:

- Find out if PHAs you serve need support in disclosing to their children. Respond by developing programs (e.g. counselling, groups, peer support).
- If direct support is beyond the ASO's capacity, establish links with other agencies that can provide support and refer PHAs to them. Ensure that the agencies you refer to are PHA friendly, confidential and safe.
- The Teresa Group has books for children about HIV and disclosure (see the Resources section of this guide)

Disclosure to Benefit Others

Some PHAs disclose their status to benefit others. Disclosure can involve going public with one's status in order to help the community come to terms with HIV and to combat stigma and discrimination. This may be particularly true in smaller communities or within a cultural context that stigmatizes HIV and HIV positive people. Disclosure may be done to protect young people against ignorance and unsafe sex or other routes such as needle sharing that can lead to infection. Disclosure in these circumstances can entail risks for the PHA, especially if HIV is a taboo subject in the community. ASOs can help by supporting PHAs who want to disclose and by holding educational events in the community, hosted or presented if possible by respected community leaders.

"I sacrificed myself by disclosing to save my community. It was worth the personal risk."

PHAs who have lived through this advise using storytelling: telling stories to educate their communities. It models the way for disclosure by others.

"Storytelling encourages the hearts of others to receive your disclosure."

"You get peace of mind when you disclose."

"Own your story. Don't live under a veil of secrecy."

If your ASO is not based in a specific cultural community, seek input from people from the appropriate cultural community about how to support PHAs from that community who wish to disclose and co-plan support activities and community events with the cultural organization. Be mindful at all times about confidentiality and letting the PHA choose when and how to publicly disclose.

Cultural Competence

Canada is a multicultural country. This is reflected in the clientele of ASOs, especially in large cities. Culture applies to everyone. Cultural differences can be based on a host of factors, which may include country of origin, ethnicity, race, socioeconomic class, religion, sexual orientation, gender, physical disabilities, age and language. The impact of recent Immigration or refugee status can be significant factors that ASOs also need to be aware of when assisting with access to health care, food insecurity and housing issues.

All of these aspects of culture need to be taken into account by ASOs in developing programs or referring PHAs to other services and programs. On the other hand, PHAs caution that ASOs can't be all things to all people. Most ASOs cannot take on every social justice issue and must choose to engage where their actions can have the greatest effect.

A PHA's culture, however they define it, has an influence on their decisions to disclose or not. PHAs suggest these ways in which ASOs can support individuals:

- Become aware of the cultural model of your ASO and how it may affect clients from other cultures. Client relationships are often diverse and are not limited to any particular culture. How can your agency be welcoming and create culturally appropriate space and safety for everyone?
- Acknowledge cultural diversity and reflect this in staff and volunteer composition where possible
- Show cultural diversity in the ASO communication tools such as websites, Facebook, brochures, posters and reports
- Educate staff and volunteers in cultural competence and creating cultural safety. Work with organizations representing cultural communities in creating these programs. Education works both ways: collaboration with cultural communities provides opportunities to encourage other organizations to include HIV education in their programs.
- Be aware of:
 - Homophobia being more apparent in some cultures than in others, and recognize that all cultures can be homophobic and HIV-phobic. Develop respectful strategies for dialogue.
 - Religious values and their impact on disclosure
 - The need for watertight confidentiality which is even more critical in some cultural contexts and in smaller communities
- Refugees or immigrants facing deportation need strict protection of information concerning their HIV status.

From the research literature: HIV positive individuals from racial/visible/ethnic minorities report more perceived, and real, stigma than white populations, and thus some studies have shown fewer disclosures in these groups. Furthermore, cultural norms specific to different communities may dictate different responsibilities towards disclosure. For example, in Asian communities, the norm of collectivism dictates that disclosure of one's HIV-status affects not only the individual, but also their families – thus, non-disclosure could be a means to avoid embarrassment for the larger family and community.

OHTN literature review

Involuntary Disclosure

“One minute you have control, and then you don’t.”

Many PHAs have had their HIV status disclosed by others. They describe the experience:

When someone else discloses your HIV status without your consent, or “outs” you, it can be devastating. The power you held to self-disclose or not has shifted, resulting in a loss of power: you have lost some of your power to tell your own story. An outing by a single person can spread like wildfire throughout an entire family or community. The person making the disclosure without your consent may be an acquaintance, an ex-lover, someone who saw you in what they judge to be an HIV/AIDS context, or even a careless health care provider. The PHA who has been disclosed against his or her will may experience a tumult of emotions that ASOs need to understand and empathize with.

Right away, you are on the defensive. Do you choose to let it affect you emotionally, physically, socially? Do you stand up and raise hell at the breach of confidence?

Or do you accept it? Are you OK with letting everyone know your story second-hand, and take it as a stepping stone toward personal and group acceptance, or does it create a wall that locks you up inside your worries and concerns? What about stigma? When people look at me, do they know, or is that all in my head? Does this disclosure cause me feelings of shame and reinforce inner stigma?

From the research literature: An HIV-person might choose to disclose in order to avoid second-hand disclosure (someone finding out from someone or somewhere else), which has a higher likelihood of affecting their identity and creating regret.

OHTN literature review

The practical consequences of involuntary disclosure can be serious: the risks include being excluded by your community and family, discrimination, loss of a job or a job opportunity, possible loss of group health benefit plans at work, and even physical attack. In the sexual realm, gay/bisexual men may be affected by the perception that different types (tops or bottoms) may be more at risk, forcing the PHA to perform sexual roles that do not fit who they are.

PHAs point out that it is sometimes possible to turn things around after one's HIV status has been disclosed by another person. Some tactics that have been used by PHAs:

- Get angry and call out the person who did the outing; they may lose respect in the eyes of others
- Register a formal complaint or undertake a law suit
- Consider the possibility that the person may have thought they were being helpful; open a dialogue with the person if the relationship is important
- Disclose more openly if you are ready to and use this as a way of educating others and possibly feeling free of the burden of secrecy

PHAs advise that ASOs can do a number of things to support PHAs who have had their status disclosed without their permission. These include:

- Prepare PHAs for the possibility of involuntary disclosure and developing strategies and supports to cope if this happens; counselling, peer and group support and role-playing are useful tools, as is practical help and legal advice/support
- Assign PHA staff and volunteers who have lived through the experience and come out the other side to mentor and support the PHA
- Ensure that the ASO is a safe place where PHAs can be sure of confidentiality

Empowering Warriors: Respecting PHAs

This guide began with a declaration that it was created in the spirit of the Ontario Accord and *Living and Serving 3* for the greater and more meaningful involvement of PHAs in all decisions and initiatives that affect them. This applies to the way that ASOs support PHAs dealing with disclosure and its consequences.

PHAs ask that ASOs:

- Understand and support PHAs facing decisions about disclosure
- **LISTEN TO PHAs:** they are the experts in living with HIV
- Trust PHAs: PHAs steer and ASOs assist in navigation
- Provide PHAs with the tools and skills – emotional, spiritual, physical and intellectual – to deal with disclosure
- Ensure that all ASO staff and volunteers have a shared vision and values concerning confidentiality and supporting the PHA’s decision to disclose or not
- Respect the PHA’s choice to disclose or not without judging that disclosure is better than non-disclosure. The ASO can accompany the PHAs in the process of deciding about disclosure but must respect the person’s choice; they are the expert about themselves and their life circumstances.
- Ensure that the ASO is inclusive of PHAs of all types when possible. If this is not possible, ensure that PHAs are supported to find services that are right for them.
- Have some staff and volunteers who are HIV positive and can serve as peer supports and mentors for PHAs
- When in doubt, ask PHAs

Resources

Canadian Aboriginal AIDS Network: <http://caan.ca>

- *Creating environments that respect the privacy and confidentiality of Aboriginal people living with HIV/AIDS* (2010): <http://caan.ca/wp-content/uploads/2010/03/Privacy-Doc.pdf>

Canadian HIV/AIDS Legal Network: www.aidslaw.ca

- *HIV non-disclosure and the criminal law: A summary of two recent decisions of the Supreme Court of Canada* (2012): <http://www.aidslaw.ca/publications/publicationsdocEN.php?ref=1328>
- *HIV non-disclosure and the criminal law: Implications of recent Supreme Court decisions for people living with HIV* (2012): <http://www.aidslaw.ca/publications/interfaces/downloadFile.php?ref=2085>
- *HIV non-disclosure and the criminal law: An analysis of two recent decisions of the Supreme Court of Canada* (2012): <http://www.aidslaw.ca/publications/publicationsdocEN.php?ref=1326>

Canadian HIV Treatment Information Exchange (CATIE): www.catie.ca

- *Undetectable blood viral load and HIV transmission risk: results of a systematic review* (March 2013): <http://www.catie.ca/en/catienews/2013-03-07/undetectable-blood-viral-load-and-hiv-transmission-risk-results-systematic-revi>
- *HIV disclosure: a legal guide for gay men in Canada*.¹ This resource is currently being updated. <http://www.catie.ca/en/changes-catie-website-response-scc-decision-hiv-and-disclosure>

Gay Men's Sexual Health Alliance: www.gmsh.ca

- *HIV disclosure: a legal guide for gay men in Ontario* (2008): http://www.gmsh.ca/documents/upload_image/989617402_990-GMHS-Legal-Guide_ENG-FNL-lowres.pdf [This resource is currently being updated]

¹ This guide is a co-publication of the Gay Men's Sexual Health Alliance and CATIE. A link to the same resource is provided under Gay Men's Sexual Health Alliance.

HIV & AIDS Legal Clinic Ontario: www.halco.org

- HIV & Criminal Law: <http://www.halco.org/areas-of-law/hiv-criminal-law>

Ontario AIDS Network: www.ontarioaidsnetwork.on.ca

- *The Ontario Accord/Living and Serving 3* (2011):
http://ontarioaidsnetwork.on.ca/living_serving.php

Positive Leadership Development Institute™:

http://ontarioaidsnetwork.on.ca/pha_leadership.php

Ontario HIV Treatment Network (OHTN): www.ohtn.on.ca

- *Disclosure of HIV positive status: Towards the development of guidelines, strategies and interventions* (2013): www.ohtn.on.ca/Documents/Knowledge-Exchange/Rapid-Responses/RR66-Disclosure.pdf
- The OHTN site has links to other articles and papers about disclosure

Positive Women's Network: <http://pwn.bc.ca>

- Disclosing your HIV status: <http://pwn.bc.ca/hiv-community/disclosing-your-hiv-status/>

African and Caribbean Council on HIV/AIDS in Ontario: www.accho.ca

- *Criminal and Victims? The Impact of the Criminalization of HIV Non-Disclosure on African, Caribbean and Black Communities in Ontario* (2010):
http://www.accho.ca/pdf/ACCHO_Criminals_and_Victims_Nov2010_LoRes.pdf

The Teresa Group: www.teresagroup.ca

- Books and other resources. See *How Do I Tell My Kids: A Disclosure Booklet about HIV/AIDS in the Family*; this booklet can be ordered.
https://teresagr.ipower.com/publications_secure.html

POZ (United States): www.poz.com

- Articles about disclosure:
http://www.poz.com/articles/HIV_Diclosure_NEWLYDX_2441_17897.shtml

THE**S+IGMA**PROJECT (United States): www.thestimaproject.org

GMFA: the Gay Men's Health Charity (UK): www.gmfa.org.uk

- The GMFA has a positive gay guide that includes a section on disclosure:
www.gmfa.org.uk/positive/disclosing-your-hiv-status/index

Participants at the PLDI™ workshop wish to thank GMFA for their informative website that helped participants prepare for the workshop and make it more successful.

“I can’t go back to yesterday because I was a different person then.”

Lewis Carroll, Alice in Wonderland

