

# NEGOTIATING DISCLOSURE

THE HIV SERO-STATUS DISCLOSURE  
TOOLKIT



WOMEN'S HEALTH  
IN WOMEN'S HANDS  
COMMUNITY HEALTH CENTRE  
INCREASE • INNOVATE • IGNITE

# ACKNOWLEDGMENTS

We would like to acknowledge and thank all of our research partners, members of the advisory committee, peers, and participants who played a pivotal role in developing the HIV disclosure support model.



## WE WOULD ALSO LIKE TO THANK THESE INDIVIDUALS FOR THEIR CONTRIBUTIONS:

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# OVERVIEW & BACKGROUND

## IN THIS SECTION

- Defining Disclosure
- Development of Model
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### Defining Disclosure

The term disclosure is used to describe the action of making new or secret information known. Within the context of HIV/AIDS, disclosure is a multi-faceted and multi-layered process; which is influenced by intersections of identity, dimensions of difference, and context. Although the experience of disclosure is unique to each individual, most will undergo similar stages of disclosure each time the disclosure process is initiated. This model provides a template that outlines the stages involved.

### Impact of Disclosure on Health & Well-being

Disclosure of HIV positive status is an important strategy for reducing HIV transmission, however when this is the only focus HIV disclosure can be a traumatizing, isolating, and painful experience. In order to adequately and meaningfully people living with HIV to disclose their status other factors must be taken into consideration. Disclosure can be an empowering experience for people living with HIV if there is adequate support and counseling throughout the process. This tool is meant to promote the understanding of challenges people living with HIV face in terms of disclosure and how service providers and organizations can strive to alleviate some of the associated stress.

### Background on the development of the model

The model was developed through a process of knowledge exchange with community stakeholders through three distinct research phases:

- 1) The development and pilot testing of the model: The process began with a literature review, a series of focus groups and key informant interviews to develop the model. Participants, service providers, and peers implemented and participated in the disclosure model in the pilot testing phase.

- 2) The development of the integration guidelines: The process began with a literature review and consultation with our partner organizations on how best to integrate the disclosure model in everyday practice.
- 3) The expansion and roll-out phase: Focus groups with youth, heterosexual black men, Gay/MSM in Toronto, and interviews in Waterloo and Niagara were conducted with to determine the adaptability of the model.

## About Women's Health in Women's Hands

Women's Health in Women's Hands (WHIWH) Community Health Centre's mandate is to provide primary healthcare to racialized women from the African, Black, Caribbean, Latin American and South Asian communities in Toronto and surrounding municipalities. We are committed to working from an inclusive feminist, pro-choice, anti-racist, anti-oppression, and multilingual participatory framework in addressing the issue of access to healthcare for our mandated priority populations encompassing gender, gender identity, race, class, violence, sexual orientation, religion, culture, language, disability, immigration status and socio-economic circumstances.

Wangari is the Program and Research Manager at Women's Health in Women's Hands, a community health centre. She is also a nationally recognized community based researcher, working with multiple stakeholders to generate knowledge and translate it into action to inform programs and policies targeted to women, particularly women from HIV endemic countries of Africa and the Caribbean. Wangari has served on various boards, working groups, advisory and review committees including the Ontario HIV Treatment Network's Scientific Review and Community Network Advisory Committees, the Ontario Advisory Committee on HIV/AIDS (OACHA) and Ministerial Council of the Canadian Strategy on HIV/AIDS. As an HIV advocate, She has led the development of local, national and international initiatives to support Black populations living in Canada and other developed countries mount effective responses to HIV/AIDS. She served as the Co-Chair of the African and Caribbean Council on HIV/AIDS in Ontario (ACCHO) from 2004 – 2010. Wangari is currently the Co-Chair of the Governing Council of the African and Black Diaspora Global Network on HIV and AIDS (ABDGN), a network she co-founded during the International AIDS conference held in Toronto in 2006. The aim of the network is to support a coordinated global response to HIV within African/Black populations living in the diaspora.

## Research Team

This research project would not have been possible without the support and input of our research team and advisory committee. We have been fortunate enough to work with several different organizations in Ontario, all of which have been instrumental in the development and expansion of the research project.

Organization	Website
Toronto People with AIDS Foundation (PWA)	<a href="http://www.pwatoronto.org/">http://www.pwatoronto.org/</a>
The Black Coalition for AIDS Prevention (Black CAP)	<a href="http://www.black-cap.com/">http://www.black-cap.com/</a>
Africans in Partnership Against AIDS (APAA)	<a href="http://www.apaa.ca/">http://www.apaa.ca/</a>
The Teresa Group	<a href="http://www.teresagroup.ca/">http://www.teresagroup.ca/</a>
CASEY House Hospice	<a href="http://www.caseyhouse.com/">http://www.caseyhouse.com/</a>
African and Caribbean Council on HIV/AIDS in Ontario (ACCHO)	<a href="http://www.accho.ca/en">http://www.accho.ca/en</a>
The AIDS Network, Hamilton	<a href="http://www.aidsnetwork.ca/">http://www.aidsnetwork.ca/</a>
Positive Living Niagara	<a href="http://www.positivelivingniagara.com/">http://www.positivelivingniagara.com/</a>
AIDS Committee of Toronto (ACT)	<a href="http://www.actoronto.org/">http://www.actoronto.org/</a>
AIDS Committee of Cambridge, Kitchener, & Waterloo (ACCKWA)	<a href="http://www.acckwa.com/">http://www.acckwa.com/</a>
Community for Accessible AIDS Treatment	<a href="http://www.hivimmigration.ca/">http://www.hivimmigration.ca/</a>
Regional HIV/AIDS Connection	<a href="http://www.hivaidconnection.ca/">http://www.hivaidconnection.ca/</a>
AIDS Committee of Ottawa	<a href="http://www.aco-cso.ca/">http://www.aco-cso.ca/</a>
Public Health Agency of Canada	<a href="http://www.publichealth.gc.ca/">http://www.publichealth.gc.ca/</a>

## How to use the toolkit

Each section begins with a brief explanation and provides insight into the intervention as well as documents to help guide you through implementing the framework at your organization. To begin, read the toolkit in its entirety and determine if you have the necessary tools, resources and organizational support to implement the intervention framework into your everyday practice. Follow the guidelines in *'Integration Guidelines for Organizations'* as they pertain to your organization. Utilize the resources available in *'Resources for Disclosure'* to add depth and context to your implementation and integration plan.

## Frequently Asked Questions:

**Q: What is the toolkit?**

**A:** The toolkit is a step-by-step guide for delivering the intervention directly to clients. There are resources to help support clients and providers with the process. These resources can be found in *'Integration Guidelines for Organizations'* and *'Resources for Disclosure'*

**Q: Who is the toolkit for?**

**A:** The toolkit is designed for organizations, service providers and peers who would like to provide support to people living with HIV who are contemplating disclosure. It is also for anyone who is interested in learning more about the disclosure model and may be interested in implementing the model in their setting.

**Q: Why should I use it?**

**A:** This toolkit can provide additional resources and guidance on how to integrate the HIV Disclosure model as a support service in an organization's day to day practice.

**Q: What about involuntary disclosure?**

**A:** At this moment in the time HIV Positive Sero-Status Disclosure Intervention only provides a support framework for voluntary disclosure. The Research Team is in the process of seeing what mechanisms can be put in place to address involuntary disclosure through the HIV Positive Sero-Status Disclosure Intervention.

**Q: I already provide HIV disclosure support, how is this model different?**

**A:** This is a tool that is meant to provide a systematic template of how to support individuals through the process of disclosure. How to navigate disclosure support can be challenging, so the hopes of this model is to provide some guidance in your everyday practice.

**Q: What do you mean by intervention? (Remove)**

**A:** In health care, action taken to improve a situation that might mean a program to help people manage their illness, surgery, or medication. In terms of this toolkit, it is used to describe the actions taken to help individuals achieve and/or learn more about HIV disclosure.

**Q: What is a case study? How can I use it? A:** A case study is particular instance of an event or situation, which is often written in story format to serve as an example to others in similar situations. Case studies help illustrate ways in which care providers can deal

with similar issues in the future. You can use the case study to test your skills as a care provider in identifying issues around disclosure.

**Q: How can I contribute to the toolkit?**

**A:** If you have any suggestions please contact the HIV Disclosure Intervention Research Coordinator: Sandra Godoy.

**Q: Who do I contact for help if I have problems?**

**A:** If you have any questions please contact the HIV Disclosure Intervention Research Coordinator: Sandra Godoy.

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# THE HIV-POSITIVE SERO-STATUS SUPPORT MODEL

## IN THIS SECTION

- Guiding Principles & Framework
- Structure & Elements
- Tools: Participant Matrix

The intervention known as “**The HIV Positive Sero-Status Disclosure Support Model**” is a 6-step process designed to guide users through the initial steps of determining the need for disclosure and the subsequent steps required for a successful disclosure to occur based on the research conducted by our team. The frameworks and guiding principles that guided the development of the model are outlined below:

### **Feminist and Critical Race**

A feminist and critical race theoretical framework emphasizes justice, fairness and rights and links research to action. It helps shed light on the organizational and structural nature of intersecting oppressions (gender oppression, racism, homophobia, etc.) and the interdependent, mutually constitutive relationship between social identities and social inequities. It connects research to resistance with emancipatory aims to challenge oppression and promote social justice.

### **Transnational Perspectives**

A transnational theoretical framework best describes the multiple and hybrid identities of migrant populations living in Canada. It recognizes that the social life of migrants is not confined to one country, that migrants take part in the social life of both societies rendering the nation state boundaries invisible.

### **GIPA/MIPA**

GIPA/MIPA values allow for the greater involvement and meaningful engagement of people living with HIV/AIDS, an approach that is grounded in human rights and recognizes the importance of inclusion.

# THE HIV-POSITIVE SERO-STATUS DISCLOSURE SUPPORT MODEL



If the need for disclosure is established, clients should be guided through the steps of the model by trained peers and/or health care personnel. Depending on the needs of the individual, the process may take a few weeks, months or extend over longer periods of time. It is up to the care provider or peer to recognize barriers and resistance to disclosure and adjust the pace of the model accordingly. As such it is recommended that the model be delivered by personnel with experience in counseling. It is recommended that the process begin with obtaining informed consent and establishing confidentiality.

## *Step 1: Acceptance & Empowerment*

Determining readiness for disclosure or any other action-based model is a subjective process, which relies on individual insight. As such, experienced care providers may be able to reach a conclusion as to a client's ability and willingness to disclose through *dialogue* and *direct observation*. Care providers and peers should look for key indicators when assessing acceptance & empowerment.

### **Key Indicators:**

- Has the client accepted the diagnosis of HIV?
  - Are they experiencing negative emotions or denial?
  - Can the client articulate their experience of living with HIV?
  - Do they self-identify as living with HIV?

Additionally, look to programs within your organization or in partner organizations that can help improve self-awareness and empowerment:

- Self-help and support groups
- Direct peer support
- Digital Stories and web-based resources

Alternatively, move forward to the next step if the client understands their diagnosis and is in an accepting frame of mind. However, it may be necessary to refer the client for further counseling with a member of your care team or work with the individual for a longer period of time.

## *Step 2: Education & Preparation to Disclosure*

### **Key Indicators:**

- How much does the client know about HIV transmission, treatment, and prognosis?

- Is the client comfortable discussing HIV?
- Is the client aware of services available to them in their community?
- Is the client aware of the repercussions of HIV disclosure?
- Is the client aware of what may happen if they do not disclose their status?

Knowledge of basic HIV transmission and treatment is essential for positive prevention of HIV to prevent transmission to partners and infants. If the client's understanding is limited in this respect, the model should be paused at this stage until the client is sufficiently able to understand their diagnosis and what it may mean if they disclose their status.

If the client has a solid level of awareness of the resources available to them (legal aid, infant feeding programs, wellness and mental health programs, income support, etc.) and can identify both positive and negative potential outcomes of disclosure, then, the client is ready for the next step.

### *Step 3: Establishing Motivation for Disclosure*

#### **Key Indicators:**

- The client can clearly state one or more reasons for disclosure (legal concerns, disclosing to their perinatally infected child or teenager, access to resources that require disclosure e.g. disability support, etc.)
- The client feels that disclosure is necessary in order to achieve a desired goal (e.g. personal relationship, legal protection, immigration status, special designation or accommodation, etc.)
- The client often initiates discussions around disclosure and asks questions

Although the client has been guided through the informed consent & confidentiality process it is important to reestablish the voluntary nature of disclosure at this stage. Based on your judgment if disclosure is necessary and voluntary the client can move on to the next step. However, if there is any amount of hesitation, please take the time to return to the previous steps and probe deeper into the preparation process. This may include gathering resources and guiding the client through the education process.

### *Step 4: Evaluating the Disclosure Environment*

#### **Key Indicators:**

- The client has a strong or reasonably good support system
- The client is comfortable interacting with members of their cultural or faith community

- The client feels safe at home, work, and among peers
- The client challenges and responds to stigma when they encounter discriminatory behavior (in general, not necessarily directed towards them)

During this stage it might be helpful to map out your client's support environment including family and friends. If the client can identify one or more individuals that can be relied upon to maintain confidentiality and provide unconditional support when needed, there is a reasonably good support system in place that can be strengthened over time.

Alternatively, if there are large gaps in the client's support environment, the development of a safety plan is necessary to ensure the client's welfare should they decide to move forward with disclosure in an obstructive environment.

## *Step 5: Assessing Potential Outcomes of Disclosure*

### **Key Indicators:**

- The client can illustrate both positive and negative reactions to their disclosure
- The client can list several ways in which disclosure might impact their health, family, happiness, future, etc.
- The client is aware of the benefits and risks of disclosure and can provide suggestions or potential solutions to resolving conflict and mitigating risks

The client can be guided through to the final stage of the process once they feel safe enough to disclose and is familiar with the established safety plan. If the client is not yet comfortable at this stage, more counseling may be needed. Reviewing previous steps in the intervention may be necessary in order to reestablish motivation and/or to reevaluate the client's environment in order to determine if there has been a change in circumstances or readiness to disclose.

## *Step 6 A: Disclosure Plan*

### **Key Indicators:**

- The client can clearly map out potential reactions and steps they can take in response to the reaction in question
- The client has chosen how they want to disclose (in person vs. over the phone), and who they want present and what their roles will be
- The client has taken into consideration where disclosure will take place (home, work, time of day, etc. and repercussions of disclosing in different spaces at different times)

- The client can outline possible sources of support for the person being disclosed to
- The client feels prepared to answer questions regarding HIV if they arise

Once the client has reached this stage successfully, it is recommended that the client and care provider/ peer develop a disclosure plan together. The client must feel comfortable with all the details of the disclosure plan. The disclosure plan should be practical and comprehensive, as it should also have sufficient detail to take into account different scenarios, potential outcomes (both positive and negative), and impacts on the client.

## *Step 6 B: Disclosure Event*

### **Key Indicators:**

- **ALL** the components of the safety plan accounted for (cell phone, cash for transportation, housing etc.)
- The client feels comfortable and understands **ALL** aspects of the safety plan
- If the client does not feel comfortable with the safety plan and would still like to disclose, revisit previous steps of the disclosure model to address any unresolved challenges or questions

At this stage of the process, clients should be encouraged to continuously monitor and express their feelings and thoughts, both negative and positive. Disclosure is a process that is wrought with emotion and therefore some level of nervousness is common. However if the client is very hesitant or exhibits extreme agitation, return to previous steps until the client is ready to move forward. In most cases 100% readiness cannot always be achieved, however once the client is sufficiently comfortable and you are confident in your assessment of and rapport with the client, the final step is to execute the disclosure plan while ensuring that all support systems are in place.

### **Things to consider after disclosure:**

- **Debrief:** will be important to address important things like partner testing, legal counsel if necessary, etc.
- **Assess:** whether additional support is required, the types of support and duration
- **Provide:** referrals as needed
- **Follow-up:** until the client indicates they no longer require follow-up support
- **Determine:** if further disclosures need to take place (the client may feel encouraged by the experience and may identify others they want to disclose to)
- **Develop:** strategies for breaches of confidentiality after disclosure

## Tools

These tools are meant to be used by service providers, peers, and participants throughout the HIV disclosure model to track progress and challenges through each step of the disclosure model.

The Learning Matrix-Participant Assessment is a template that should be used by service providers to gauge the client's level of comfort with each step. The tool is meant to outline whether or not more time should be spent on a particular step or whether or not to move to the next step.

## Tools: Learning Matrix-Participant Assessment

Score Levels	Step 1	Step 2	Step 3	Step 4	Step 5	Step 6
3	They are comfortable with their diagnosis They are in control of their health care decisions	Currently uses community services is aware of the repercussion of disclosure	Has clear goals around disclosure Comments reflect application of critical thinking Has verbalized who they want to disclose to	The client has at least 2-3 friends or family members with whom they are in regular contact The client feels safe in their environment and does not fear in-	Potential outcomes are known and clearly focused in an organized and thoughtful manner Client thinks in a logical pattern to support solutions	The client has constructed a disclosure plan that is well thought out The client is looking forward to the disclosure event
2	The client is coming to terms with their diagnosis and is seeking help from a peer or counsellor They requires some support with their health care decisions	The client uses one community based service organization The client is unsure what might happen if they discloses	The client may want to disclose in the future but is currently unsure Has given disclosure some thought The client has an idea of who they may want to disclose to	The client has 1-2 friends or family members with whom they are in regular contact The client is not aware of the safety issues in their environment	Potential outcomes are unclear, and needs time to think them through Their thought patterns are influenced by emotional experiences	The client requires significant support in developing a disclosure plan The client is hesitant about the disclosure event
1	The client is denial about their HIV diagnosis Client is unsure or unwilling to seek help for their HIV treatment	The client is not connected with any other service providers The client is hyper-aware of the negative repercussions of their HIV disclosure	The client has no intention to disclose their status to anyone The client's comments reflect internalized stigma	The client has isolated themselves and/or lacks any social support The client is afraid that someone might inadvertently discover their status	Only negative outcomes are highlighted Thoughts change from session to session Pattern of thought veers towards the negative	The client does not want to develop a disclosure plan The client has no plans to disclose

Level 3 is indicative of smooth step-wise transition through the intervention

Level 2 indicates marginal progression, but can transition smoothly with added support

Level 1 indicates the client needs major support and may not be ready for the intervention



# INTEGRATION GUIDELINES

## IN THIS SECTION

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- The HIV-positive Sero-Status Disclosure Support Model
- Getting ready to adopt the model
- Suggested training for staff and peers
- Training evaluation & learning experience
- Additional resources

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## SECTION 1: INTEGRATION GUIDELINES FOR ORGANIZATIONS

### **What are the ‘Integration Guidelines for Organizations’?**

The Integration Guidelines for Organizations was created to support organizations that provide care and support services to people living with HIV to implement and integrate the HIV-positive sero-status disclosure support model in Ontario. The recommended steps are outlined to provide organizations with the information they would need to get started and use in the process of preparing for the integration and implementation of the HIV disclosure support model.

### **Why were the ‘Integration Guidelines for Organizations’ created?**

The idea of creating the integration guidelines originated from a think-tank held in 2010 in Toronto that was organized to share findings from the pilot testing of The HIV Positive Sero-Status Disclosure Model. Participants of the think-tank highlighted the need to have clear guidelines to help organizations adopt the HIV disclosure support model in practice. In response to this suggestion, the team embarked on investigating the most effective strategies for organizations to adopt and implement the HIV disclosure support model as part of their care and support programs; in order to help clients who are looking to voluntarily disclose their HIV-positive status to significant others.

The information provided in this document came from numerous investigations including a literature review on the most effective methods of model integration and 12 organizational meetings to identify unique issues that organizations may face in implementing the HIV Positive Sero-Status Disclosure support model. These meetings were held between October 2014 and March 2015 across the province to:

- a) Familiarize organizations who were interested in adopting the HIV disclosure model with the disclosure model itself
- b) Determine what was needed to integrate the HIV disclosure model into support and care services provided by each organization based on their unique infrastructure
- c) Identify the trainings required for organizations to deliver the model effectively

Together with a focus group on facilitators and inhibitors of organizational integration of the HIV disclosure support model, these guidelines were created.

## **What is the Purpose & Objectives of the ‘Integration Guidelines for Organizations’?**

The purpose of this manual is to help organizations that provide care and support services to people living with HIV in Ontario to plan, integrate, implement and evaluate the HIV disclosure support model. The ‘Integration Guidelines for Organizations’ aims to bridge the gap between research and practice by assisting organizations that would like to implement the disclosure support model through a set of guidelines to follow. The objectives of these guidelines are to:

- a) Facilitate the implementation of the HIV disclosure support model by translating research into practice
- b) Provide strategies that can be tailored to reflect the composition and practices of different organizations throughout the process of integrating the HIV disclosure support model
- c) Assist organizations plan, implement and evaluate the HIV disclosure support model

## **Who is the intended reader of the ‘Integration Guidelines for Organizations’?**

These guidelines are intended for AIDS Service Organizations (ASOs) and other organizations that provide care and support services for people living with HIV across Ontario. These guidelines are written primarily for service providers and agencies that would like to adopt and implement the HIV-Positive Sero-Status Disclosure Support Model.

## **How do you use the ‘Integration Guidelines for Organizations’?**

The ‘Integration Guidelines for Organizations’ is part of this disclosure *toolkit* developed by Women’s Health in Women’s Hands (WHIWH) in partnership with 13 different organizations across the province (Appendix A). This *toolkit* is meant to support the organizational uptake and implementation of the HIV-Positive Sero-Status Disclosure Support Model for persons living with HIV in Ontario. The guidelines should be used in conjunction with other materials developed for the *toolkit*, which includes:

- Tab 1. Overview and Background
- Tab 2. The HIV-Positive Sero-Status Disclosure Support Model
- Tab 3. Integration Guidelines for Organizations
- Tab 4. Additional Resources: Community Resources for HIV/AIDS Disclosure

## SECTION 2: THE HIV-POSITIVE SERO-STATUS DISCLOSURE SUPPORT MODEL

### **What is the HIV-Positive Sero-Status Disclosure Support Model?**

The HIV-Positive Sero-Status Disclosure Support Model was created to provide a systematic, step-by-step template that can be used to provide support to individuals throughout the process of disclosing their HIV-positive status. The intervention outlines the importance of providing holistic, collaborative, and ongoing support throughout the disclosure process in order to ensure the wellbeing and safety of individuals seeking support.

### **What are the Goals & Objectives of the ‘HIV-Positive Sero-Status Disclosure Support Model’?**

The objectives of the model are to:

- Provide an HIV-Positive Sero-Status Disclosure Support Model that takes into consideration race, gender, sexuality and other socio-cultural variables that influence HIV-positive status disclosure
- Provide a framework that allows a person living with HIV to inform and determine how the disclosure action plan will develop and be implemented
- Evaluate potential risks and effects of disclosure to maximize their wellbeing and safety
- Train peers who have disclosed to serve as a support mechanism for organizations based on their lived experience

The practice-based goals of the disclosure support model are to:

- Provide a step-by-step framework to guide people living with HIV and their service providers to go through the process of disclosure
- Provide resources and support mechanisms needed throughout the disclosure process
- Foster discussions on issues impacting disclosure
- Identify challenges and opportunities/options
- Evaluate potential risks and outcomes
- Identify points where a person can withdraw from the disclosure process if readiness has not been achieved yet

### **How was the HIV-Positive Sero-Status Disclosure Support Model developed?**

Three distinct phases mark the development of the HIV-Positive Sero-Status Disclosure Support Model.

1. Developing and pilot testing ‘The HIV-Positive Sero-Status Disclosure Support Model for African Caribbean and Black Women’: An extensive literature review was conducted to explore existing data on disclosure experiences. The data was analyzed according to

emerging themes. Interviews with key informants (n=4), and 4 focus groups (n=30) were conducted with HIV-positive women who had and had not disclosed, as well as service providers. Six organizations and 10 peers were trained to support pilot testing of intervention with women who indicated they were contemplating disclosure. In this phase the disclosure model was shown as being effective (Tharao, Muchenje, and Mehes, 2013).

2. The development of the integration guidelines: The process began with a literature review and consultation with our partner organizations on how best to integrate the disclosure model in everyday practice.
3. The expansion and roll-out phase of 'The HIV-Positive Sero-Status Disclosure Support Model': Focus groups with youth, heterosexual black men, Gay/MSM in Toronto, and interviews in Waterloo were conducted to determine the adaptability of the model. The components of the original model were adapted and the model is now known as "The HIV Positive Sero-Status Disclosure Support Model". Refer to Tab 1 and Tab 2 for specific information on the HIV-Positive Sero-Status Disclosure Support Model.

## SECTION 3: GETTING READY TO ADOPT THE HIV-POSITIVE SERO-STATUS DISCLOSURE SUPPORT MODEL

### Getting Started

“...since various organizations have different cultures, standards and ways of doing things, the process of integration would likely differ from one organization to the other” (Attakora et al., 2014, pg. 12).

We begin this section by acknowledging that each organization is different and has a unique composition of programs, services, assets, resources, and clients. The challenges and strategies used to implement the HIV-positive sero-status disclosure support model will differ from organization to organization. For this reason we have provided an assessment template for organizations looking to implement the HIV disclosure support model. This assessment will help organizations determine what they have in place to support the integration of the HIV disclosure model, what may be missing, and how to address any gaps.

The first step is to identify who will be conducting the assessment. This could be an individual staff within the organization or a committee of staff who would conduct the assessment. We suggest that it be a collaborative process between service providers and management. This assessment is composed of six open ended questions, so that organizations can identify the next steps and areas of improvement based on the organization’s programs, services, and staff. *Figure 2. Assessment Template for Model Implementation* lists the questions included in the assessment. A printer friendly version can be found in the resource section.

**Figure 2. Assessment Template for Model Implementation**

1. How do you approach HIV positive disclosure as an organization?
2. What are some of your successes and challenges in supporting PHAs with disclosing their HIV positive status within your organization?
3. How do you see the HIV-Positive Sero-Status Disclosure Support Model being operationalized as part of your regular service delivery?
4. What challenges do you foresee in operationalizing the disclosure support model within your service delivery?
5. What training might your organization need to support the integration and implementation of the HIV-Positive Sero-Status Disclosure Support Model?
6. Does your organization utilize the services of volunteers/peer support?
  - If so, how do you envision their role in the disclosure support process?
  - If not, would you integrate peer support in the process?

**Ensuring confidentiality**

HIV-positive status disclosure is an emotional and multifaceted process. Before offering your clients support on this journey, it is important to ensure your organization can provide a safe and confidential space for HIV disclosure conversations. We encourage organizations to examine the physical space of their agency. Not all clients are open and/or feel comfortable with their status. Some clients are reluctant to access support services due to the fear of involuntary disclosure. Some organizations may have open spaces to encourage an open and friendly environment; however it is important to have space that is designated for private conversations. Shared offices and borrowed spaces can hinder the process of disclosure. You want to make sure that once a client is being taken through the HIV disclosure support model that the process is uninterrupted, and that the conversations are documented and managed in a secure and confidential manner. We encourage organizations and staff to take all measures necessary to ensure that clients who walk through their doors feel both comfortable and reassured that the agency takes confidentiality and privacy measures very seriously.

<b>Ensuring Confidentiality</b>	<b>Task complete?</b>	<b>If No, specify next steps</b>
Have you reviewed your confidentiality and recording keeping policies and practices with staff?		



Do you have private space to offer disclosure support?		
Do you have office cabinets that lock if hard copies of client files are being stored?		
Do you have individually assigned computers/logins that are secure and password protected?		

*\*Please note: This checklist along with the ones to follow have been compiled in one document that can be found in the resource section*

### **Assess organizational policies & address liabilities**

Many organizations do not have a systemic process to support HIV disclosure. It's important to establish how the HIV disclosure support model fits into current policies, mandates, and practices. We encourage organizations to analyze how the HIV disclosure model will operate as part of its overall service delivery. Further, we encourage organizations to create transparent policies and practices outlining how they will support the staff and or peers/volunteers implementing the HIV disclosure model.

Supporting individuals through their HIV disclosure process can raise questions for service providers trying to navigate between their professional codes of conduct and/or practices and their concern for equitable and ethical treatment of a client, particularly in the context of criminalization of HIV non-disclosure. Through focus groups and consultations with organizations, many service providers who support people living with HIV discussed frequently being concerned with liability because they did not know if they were implicated in their clients' disclosure decisions and whether or not they would be protected by their organizations if they were (Barry, 2014).

Prior to implementing the HIV disclosure support model, organizations have a responsibility to inform all staff that are involved on what their legal responsibilities are and what they would be accountable for by law. Generally, service providers in the field have to come up with creative ways to document and support their clients. If the support of peers and/or volunteers will be utilized in the HIV disclosure process, it is also necessary for the organization to identify what peers and volunteers are liable for and how the organization will support staff, peers, and/or volunteers involved in providing support.

<b>Assess organizational policies and address liabilities</b>	<b>Task complete?</b>	<b>If No, specify next steps</b>
Do you have an HIV disclosure policy and position statement?		

Have you informed staff what they are legally responsible and liable for while participating in supporting clients through the HIV disclosure process?		
Have you informed peers/volunteers of any liability concerns?		
Have you outlined the role the organization will play in supporting and protecting staff, peers, or volunteers throughout the implementation of the disclosure model?		
Have you created a transparent internal process of what will occur if client files are subpoenaed?		

### **Identify staff that can be involved in supporting disclosure**

A client’s entry point to an organization may vary. In the planning and preparation phase of the integration, it is important to outline who the first point of contact for clients should be, who they should see afterwards and what services they should access; creating a template for service delivery. For smaller organizations, this pathway is often times straightforward and easy to monitor. For larger organizations clients may enter through different pathways and may see one or several staff within the organization.

Identify the number of staff and peers you would like to implement the disclosure model, what their roles and positions are, what skill sets they have, what resources and tools the organization has, and areas for improvement. For those who would be directly working with clients/service users, it is important to conduct an assessment of their knowledge of HIV/AIDS, associated challenges, and their understanding of HIV disclosure. This is an important step as service providers are the main point of contact with clients. Service providers have the potential to form and develop trusting relationships with their clients, which can help facilitate the disclosure process.

It is also important to inform all staff involved in implementing the HIV-positive disclosure model on what their roles are. It is important that all staff involved understand that their role is not to persuade clients to disclose, rather their role is to provide support with a very clear understanding that the end goal is not necessarily disclosure. The goal is to explore the possibility of disclosure, assess potential outcomes, and create a safety plan if the person living with HIV feels that they are ready to disclose.

<b>Identify staff that can be involved in supporting disclosure</b>	<b>Task complete?</b>	<b>If No, specify next steps</b>
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Have you created a process for client's entry/pathway to services in your organization?		
Have you identified which staff will be involved in supporting clients through disclosure?		
Have you clearly outlined the responsibilities and roles of the staff involved in the disclosure model?		
Have you identified any capacity-building training needs for your organization and staff?		
Have you organized meetings with all appropriate staff to give updates on the integration and implementation process?		

### Identify clients who may benefit from participating in the model

Organizations generally serve different populations and or demographic groups based on either their catchment area or mandate. Some of these groups may have different challenges disclosing their HIV status compared to others – this difference should not be ignored. It is important for the organization to identify what population they are most suitable to serve and set a realistic target given the services they provide and the organization's area of expertise. It is important for the organization to set guidelines for how they will promote the intervention in their organization and the referral process (es).

Identify clients who may benefit from participating in the model	Task complete?	If no, specify next steps
Have you identified which population/demographic is suitable to receive the disclosure support given your area of expertise?		
Have you determined how you will promote the model within your organization?		
Have you determined what the referral process(es) will be for the person disclosing and the one being disclosed to?		

### Assess & identify community resources

Assessing your resources and identifying what you have in place to support the integration process is essential in ensuring the process is a success. For some organizations, they may have most of the resources they need to support individuals, as well as the person being disclosed to,

in order to successfully go through and complete the disclosure journey. This may include having a support worker, social worker, therapist, family doctor, a testing site, etc., all under one roof to support a client who is going through the process.

In some instances, organizations do not have all the resources to successfully implement all aspects of the HIV disclosure support model without referrals. For instance, through our investigations we found that most ASOs do not have the internal resources to provide trauma therapy, which is a significant component of the disclosure model. In this process, we encourage organizations to identify their support networks in advance and liaise with community partners and collaborators on ways to support their clients' journeys.

<b>Assess and identify community resources</b>	<b>Task complete?</b>	<b>If No, specify next steps</b>
Have you identified community resources that will assist you through the implementation of the disclosure model?		
Have you created an understanding of what additional support they will provide your organization?		
Have you created a referral pathway for both internal and external resources needed?		

### **Identify organizational & staff capacity-building needs**

Once you have gone through this section you will have a sense of how your organization can support the HIV disclosure support model and what may be missing to ensure a seamless integration process and a successful disclosure support program. Once this checklist is complete an organization will have a sense of what the next steps entail. The answers will indicate the capacity-building plans needed for staff and the organization itself to support the process as a whole. The complete checklist can be found in the resource section.

## SECTION 4: SUGGESTED TRAINING FOR STAFF AND PEERS

### Possible training topics

Throughout the creation of the HIV-disclosure model and consultations with organizations and their service providers on how to implement the HIV disclosure model it became clear that additional trainings would be necessary. A list of training topics is outlined below; knowledge of each of these topics is integral to implementing effective HIV-disclosure support. However, depending on your organization or staff's area of expertise, you may only need training on a few of these topics. Therefore it is important to define your training goals based on the results of Section 3.

*Possible Training Topics include:*

- Immigration and HIV
- Anti-Racist and Anti-Oppressive (ARAO) framework in everyday practice
- Self-care
- Implementation training (intervention steps, role playing, tracking forms, evaluation)
- HIV 101 & 201
- Training on documentation
- Sex Positivity
- Law vs. Good Health Practices
- Disclosing to children

The trainings that you chose should be mandatory and be offered to staff and peers before organizations start using the model. The selected trainings will cover all the practical steps in implementing the model, as well as other topics that have been proven to be useful for staff and peers.

Implement suggested training for staff and peers	Task Complete?	If No, specify next steps
Have you defined your training goals?		
Have you set up trainings to reflect your learning goals?		
Have you created an evaluation for each training received to ensure the training goals have been met?		
Have you identified the resources required to implement the training?		

## **Who is required to attend the training?**

The decision of who gets to attend training is entirely up to organizations. We recommend that all staff and peers who provide support to clients within the organization e.g. support workers, social workers, therapists/counsellors, etc. attend and complete all components.

## **What is needed to complete the training?**

Staff and peers who are selected to attend this training must commit to the training schedule and time. They must attend all required trainings and participate in activities as directed. Some of the training sessions might last all day, while others might require staff and peers to sit in front of a computer for a number of hours. Please ensure that you have all the details of what the training entails and make the necessary arrangements with your representative organization before you get started. Organizations should liaise with the organizing bodies to ensure they have the following information:

- A clear schedule and agenda outlining the training start date and time
- Names of who will be sent to the trainings
- If there are any costs associated with attending the sessions (i.e., travel, meals and accommodations), who would cover the costs?

Organizations are encouraged to offer their staff additional training or resources that they feel would strengthen their skills and knowledge in supporting their clients through the HIV disclosure process.

## **Review staff and peer learning experience**

Before you attend trainings, you would have identified what you want to learn from the experience. The evaluation strategies you employ need to be structured to determine whether or not your goals have been met. Things to evaluate include:

- Instructors/educators or event facilitators
  - If the facilitator/instructor communicated clearly
- Training curriculum
  - Whether or not the information you received was clear, easy for you to understand and relevant
  - Whether or not the curriculum covered all of the things you wanted to learn during the training sessions
- The event and learning environment
  - Whether or not it was a positive space/environment for learning and exchanging ideas

Staff and peers should also do a self-evaluation at the end of the training. Self-evaluation questions for staff and peers may include:

- What have I learned from attending these trainings?
- What elements will I use in supporting clients?
- What will I do differently?

- Am I able to start utilizing the model to support clients with little or no guidance? If not, do I know who to contact for additional support?
- Am I able to teach others what I have learned?

Evaluation of the learning experience	Task Complete?	If No, specify next steps
Did you administer evaluations after the training?		
Are training participants satisfied?		
Are any additional resources/training necessary?		

## SECTION 5: INTRODUCING ‘THE HIV-POSITIVE SERO-STATUS DISCLOSURE SUPPORT MODEL’

If all goals are met than we recommend organizing another internal meeting within your organization to start planning how you would generate awareness within the organization and your community at large of the HIV disclosure support services you are offering. If learning goals are not met, you may want to contact the project leader/organizer to arrange further training and support for your staff.

### **Raising awareness within your organization and community**

The best way to introduce your disclosure program is to identify a variety of strategies for getting the word out. Through our consultation meetings with the 12 organizations, the suggestions made by staff in terms of introducing the HIV disclosure model to clients/service users are as follows:

- Directly informing clients/service users who may benefit from the model
- Giving presentations - to your clients/service users, local community members, community partners, etc.
- Creating resources: posters/pamphlets/video campaigns promoting the service
- Welcome packages
- Support groups
- One-on-one sessions
- Agency website
- Awareness campaigns

The above strategies are only suggestions on possible ways organizations can spread the word about the HIV disclosure support model and the support the organization is providing for clients to go through the process. We understand each organization is unique and would come up with their own creative ways of introducing their new disclosure program and engaging their clients. Once several clients have participated in the HIV disclosure support model, it is important to solicit their feedback in order to re-evaluate if any changes need to be made in how the model is implemented.

<b>Introduction of the HIV disclosure support model</b>	<b>Task complete?</b>	<b>If No, specify next steps.</b>
Have you created a plan on how to introduce and promote the model?		
Have you created a flexible timeline for its rollout?		



## SECTION 6: ADDITIONAL RESOURCES

### **Getting Started: Assessment Template for Model Implementation**

*\*The aim of this assessment is for organizations to discuss how the HIV disclosure intervention fits into the organizations' overall service delivery and determine what work needs to be done to ensure its effective implementation within the organization.*

1. How do you approach disclosure as an organization?
2. What are some of your successes and challenges in supporting PHAs with disclosing their HIV positive status within your organization?
3. How do you see the HIV disclosure model being operationalized as part of your regular service delivery?
4. What challenges do you foresee in operationalizing such a model within your service delivery?
5. What training would your organization need to support integration and implementation of the model?
6. Does your organization utilize the services of volunteers/peer support?
  - If so, how do you envision their role in the process?
  - If not, would you integrate peers in supporting the process?

Organizational Checklist

Checklist Items	Task complete? Yes/No	If No, specify next steps
<b>Getting Started</b>		
Completion of Getting Started: Model Integration Questions		
<b>Ensuring Confidentiality</b>		
Have you reviewed your confidentiality and recording keeping policies and practices with staff?		
Do you have private space to offer disclosure support?		
Do you have office cabinets that lock if hard copies of client files are being stored?		
Do you have individually assigned computers/logins that are secure and password protected?		
<b>Assess organizational policies and address liabilities</b>		
Do you have an HIV disclosure policy and position statement?		
Have you informed staff what they are legally responsible for while participating in supporting clients through the HIV disclosure process?		
Have you informed peers/volunteers of any liability concerns?		
Have you outlined the role the organization will play in supporting and protecting staff, peers, or volunteers throughout the implementation of the disclosure model?		

Have you created a transparent internal process of what will occur if client files are subpoenaed?		
<b>Identify staff that can be involved in supporting disclosure</b>		
Have you created a process for client's entry/pathway to services in your organization?		
Have you identified which staff will be involved in supporting clients through disclosure?		
Have you clearly outlined the responsibilities and roles of the staff involved in the disclosure model?		
Have you identified any capacity-building training for your organization and staff?		
Have you organized meetings with all appropriate staff to give updates on the integration and implementation process?		
<b>Identify clients who may benefit from participating in the model</b>		
Have you identified which population/demographic is suitable to receive the disclosure support given your area of expertise?		
Have you determined how you will promote the model within your organization?		
Have you determined what the referral process(es) will be for the person disclosing and the one being disclosed to?		
<b>Assess and identify community resources</b>		
Have you identified community resources that will assist you through the implementation of the disclosure program?		
Have you created an understanding of what additional support they will provide your organization?		

Have you created a referral pathway for both internal and external resources needed?		
<b>Implement required training for staff and peers</b>		
Have you defined your training goals?		
Have you set up trainings to reflect your learning goals?		
Have you created an evaluation for each training that will be received to ensure the training goals have been met?		
Have you identified the resources required to implement the training?		
<b>Evaluation of the learning experience</b>		
Did you administer evaluations after the training?		
Are training participants satisfied?		
Are any additional resources/training necessary?		
<b>Introduction of the model</b>		
Have you created a plan on how to introduce the model?		
Have you created a flexible timeline for its rollout?		

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Attakora, D., et al. (2014). Intervention on Disclosure of HIV-Positive Status for African Caribbean and Black Women: Organizational Integration (Institutionalization) of Intervention. *Literature Review Report (Draft)*, pp. 26.

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James, L. (2011). An HIV Discloser Intervention, Model & Pilot Project for African, Caribbean and Black Canadian Women Living with HIV in Canada. *HIV Disclosure Think Tank Report*, pp. 14

**Appendix A: Partnering Organizations of The HIV-Positive Status Disclosure Intervention Project**

1. Women's Health in Women's Hands (WHIWH) - CHC
2. Africans in Partnership Against AIDS (APAA)
3. Teresa Group
4. Black CAP
5. Toronto PWA
6. African and Caribbean Council on HIV/AIDS in Ontario (ACCHO)
7. The AIDS Network, Hamilton
8. Positive Living Niagara (PLN)
9. AIDS Committee of Cambridge, Kitchener, Waterloo & Area (ACCKWA)
10. AIDS Committee of Ottawa (ACO)
11. The AIDS Committee of Toronto (ACT)
12. Community for Accessible AIDS Treatment (CAAT)
13. Regional HIV/AIDS Connection (RHAC)



## Tab 4. Additional Resources: Community Resources for HIV/AIDS Disclosure

Women's Health in Women's Hands Community Health Centre

Agency	Resource	Resource Overview
<p><b>CATIE</b></p>	<p>Sharing together for Life Canadian</p> <p><a href="http://www.catie.ca/en/pc/program/s/haring-together-life?tab=quick-facts">http://www.catie.ca/en/pc/program/s/haring-together-life?tab=quick-facts</a></p> <p>*PDF in downloads is mainly their meeting and workshop guide, with testimonials. The meeting is in 9 sections, each focusing on different stages of disclosure along with activity sheet. Appendix contains resources like brochures, fact sheet, and booklets (pages 183-185). Some Q&amp;A for program facilitators are on pages 31-35.</p>	<p>'Sharing Together for Life' is an HIV disclosure program that was designed and assessed through a community research project undertaken by the Canada Research Chair in Education and Health at the Université du Québec à Montréal (UQAM). The program was designed to help women better understand the impact of disclosure or non-disclosure of their HIV-positive status in different situations and to help them set up with a permanent support system.</p> <p>The program is made up of a series of nine workshops facilitated by a service provider and a HIV-positive woman helps participants to share, learn and think about the potentially sensitive issue of disclosing their HIV-positive status.</p>
<p><b>AIDS Bereavement &amp; Resiliency Program Ontario</b></p>	<p>Turning to One Another Network</p> <p><a href="http://abrpo.org/program/turn-to-one-another/">http://abrpo.org/program/turn-to-one-another/</a></p> <p>*In Downloads, Part A is facilitator training skills, Part B is emotional dimensions of peer support with activity sheets, and Part C is facilitator competencies, includes debriefing with assessment worksheets</p>	<p>'Turning to One Another: AIDS Service Organization Workers Engaging with People Living with HIV/AIDS to Bring the Greater Involvement of People Living with HIV/AIDS to Life' was a project initiated in 2009, working with pilot site ASOs in Ontario, to develop new processes and resources. The purpose of TTOA is to work with people living with HIV/AIDS (PHAs) and staff of AIDS Service Organizations (ASOs) in Ontario to concretize the experience of meaningful involvement for PHAs.</p> <p>There are 13 TTOA ASO Pilot Site Partners across Ontario, which support and collaborate with Peer Facilitators to create and deliver on-going local programs. They also share local ideas and practices to help develop the provincial framework.</p>

<b>Canadian HIV/AIDS Legal Network</b>	<p>HIV Disclosure and the Law: A Resource Kit for Service Providers</p> <p><a href="http://www.aidslaw.ca/site/hiv-disclosure-and-the-law-a-resource-kit-for-service-providers/">http://www.aidslaw.ca/site/hiv-disclosure-and-the-law-a-resource-kit-for-service-providers/</a></p>	<p>This Resource Kit is intended to provide both PHAs and service providers with useful information and tools to make informed and empowered choices about how to respond to criminalization of HIV non-disclosure.</p>
<b>Canadian HIV/AIDS Legal Network</b>	<p>Immigration and Travel to Canada for People Living with HIV: Questions and Answers</p> <p><a href="http://www.aidslaw.ca/site/canadas-immigration-policy-as-it-affects-people-living-with-hiv-questions-and-answers/">http://www.aidslaw.ca/site/canadas-immigration-policy-as-it-affects-people-living-with-hiv-questions-and-answers/</a></p>	<p>People living with HIV are allowed to travel to Canada. However, HIV status is one factor considered by the Government of Canada when deciding if a person can stay in Canada for an extended period of time. This Q&amp;A provides information on how Canadian immigration law and policy affect people living with HIV who wish to come to Canada.</p>
<b>Canadian HIV/AIDS Legal Network</b>	<p>Women and HIV – “Women and the Criminalization of HIV Non-Disclosure”</p> <p><a href="http://www.aidslaw.ca/site/women-and-hiv-women-and-the-criminalization-of-hiv-non-disclosure/">http://www.aidslaw.ca/site/women-and-hiv-women-and-the-criminalization-of-hiv-non-disclosure/</a></p>	<p>This is one in a series of four info sheets on the human rights of women living with or vulnerable to HIV in Canada.</p>
<b>Ontario Provincial Resource for ASO’s in Human Resources (Ontario’s AIDS Network)</b>	<p>Toolkit  <a href="http://ontarioaidsnetwork.on.ca/oprah/toolkit/">http://ontarioaidsnetwork.on.ca/oprah/toolkit/</a>  * To gain access to the OPRAH Toolkit, you must first become a member of the site. If you fill out the form your registration will be reviewed, and after a maximum of 48 hours, approved to access the Toolkit.</p>	<p>The Toolkit has been designed to provide important information, tools and templates to help ASOs manage ongoing Human Resources requirements. Materials posted on the OPRAH online toolkit are for HR processes, policies, etc. that reflect best practices and legislative compliance and there to support employers with actual tools and templates.</p>
<b>Ontario Organizational Development Program</b>	<p>Policy and Practice Toolkit for Ontario ASOs on Clients’ HIV Disclosure Decisions and Process</p>	<p>This toolkit provides ASOs a framework to assist in developing policies and practices that support people living with HIV/AIDS (PHAs) to control and navigate HIV disclosure decisions and actions.</p>



<http://oodp.ca/media/OODP-HIV-Disclosure-Policy-Toolkit-FINAL-Aug-2015.pdf>

<p><b>The Coalition for Children Affected by AIDS</b></p>	<p>Difficult Decisions: A Tool for Care Workers.</p> <p><a href="http://careworkerethics.org">http://careworkerethics.org</a></p> <p>*PDF format: Contains the Four Step Tool, a Code of Ethics, 3 examples of ethical dilemmas resolved using the tool, and a Pocket Guide to Handling Ethical Dilemmas in the Field.</p>	<p>The Coalition for Children Affected by AIDS has co-lead an international working group, which has launched a tool and guidance to assist care workers in managing ethical dilemmas when providing services to children and families of the most stigmatized and marginalized populations.</p> <p>The tool and guidance supports care workers to make good decisions, in partnership with families, to increase protection for women and children, and to reduce discriminatory behavior.</p>
<p><b>One World Trust</b></p>	<p>The Code of Good Practice for NGOs Responding to HIV/AIDS</p> <p><a href="http://www.oneworldtrust.org/csoproject/cso/initiatives/333/the_code_of_good_practice_for_ngos_responding_to_hiv_aids">http://www.oneworldtrust.org/csoproject/cso/initiatives/333/the_code_of_good_practice_for_ngos_responding_to_hiv_aids</a></p>	<p>The Code of Good Practice for NGOs Responding to HIV/AIDS sets out an extensive outline of guiding principles which apply a human rights approach to the range of HIV/AIDS-specific health, development and humanitarian work undertaken by NGOs responding to HIV/AIDS. The Code also includes organizational and programming principles addressing issues such as governance, research, service delivery, programs and advocacy work.</p>
<p><b>Positive Leadership and Development Initiative</b></p>	<p>NOW WHAT? The Possibilities of Disclosure- A Guide by HIV Positive People for AIDS Service Organizations and Their Allies</p> <p><a href="http://pldi.ca/now-what-possibilities-of-disclosure/">http://pldi.ca/now-what-possibilities-of-disclosure/</a></p>	<p>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 ASOs in supporting PHAs who are wondering about disclosure.</p>

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