



## THE TERESA GROUP DISCLOSURE OPERATIONAL POLICY AND PROCEDURES

### 1. Context

The Teresa Group serves both those dealing with disclosure and those who may be impacted by disclosure issues. Over the years the agency has been called upon to provide counselling to many, responded to the media and dealt with multiple levels of judgment among clients and staff. Disclosure issues have been a stressor to the organization for staff and clients and with our partner agencies.

### 2. Principles

The Teresa Group commits to the following:

- Making available to all clients both this policy and information about related programming options;
- Orientating all PHAs, other clients, staff, volunteers (including Board members) and students to this policy and its associated programming options;
- Requires all staff, students and volunteers to sign a commitment to confidentiality (see Confidentiality Policy)
- Reviewing operational practices as part of regular evaluation cycles to ensure policy adherence;
- Ensuring a safe and supportive environment;
- Ensuring that we are competent at handling the complexities of HIV disclosure issues and at resolving the conflicts that may result from such disclosures.

### 3. Program Standards

The Teresa Group programming will include the following elements and topics to assist people living with HIV to control and navigate their HIV disclosure options, decisions and actions. The way in which The Teresa Group implements these policies, including appropriate referrals at all steps and any current interventions being provided, is outlined in Section 4, Application of Program Standards & Principles.

#### a. **Reflection & Decision making:**

- Self-acceptance – dealing with the impacts and personal feelings of an HIV diagnosis and experiences of living with HIV;
- Normalizing disclosure considerations, discussions and decisions;
- Educating PHAs and others about HIV;
- Understanding legal implications, rights and responsibilities (as appropriately understood through information or formal legal advice such as HALCO);

- Acknowledging and exploring stigma and its impact on disclosure;
- Exploring potential safety issues in disclosure—for instance the potential for violence from spouses, family members, or for safety in housing or employment;
- Exploring cultural values;
- Identifying the individual risks, benefits, purpose and goals for possible disclosures;
- Supporting clients to resolve any ethical considerations in choosing to disclose or not to disclose;
- Making a disclosure list – exploring who could be disclosed to now, who might be disclosed to later and who might not be disclosed to;
- Determining whether to further explore specific disclosure situations;
- Exploring specifically how disclosure of a parent’s HIV status will affect children and adolescents;
- Exploring whether disclosure to a child or adolescent is done with proper preparation and support, and according to recognized standards;
- Ongoing reflection and review of disclosure journeys and processes.

**b. Planning & Preparation**

- Maximizing benefits and mitigating risks;
- Testing the waters - hinting and probing for stigma, safety issues, and perceptions of HIV by those to whom the disclosure will be made;
- Disclosing to an ally – starting or testing disclosure with someone known to be HIV+ or known to be an ally;
- Where a decision to disclose is made, preparing a plan and strategies;
- Determining appropriate timing and setting – consider mental state of those involved, not being rushed, safety, and access to support;
- Choosing a method or medium – the majority of disclosure experiences are face to face but consider if there are circumstances where another method or medium (phone? letter?) that might be beneficial;
- Identifying the limits and boundaries of how much to disclose and share;
- Tailoring disclosure message and content – type, duration and depth of relationship, recipients’ knowledge of HIV, reason for disclosing;
- Consider and plan what and how much to share, particularly related to means of infection, stigma and/or trauma;
- Preparing for possible responses; and
- Establishing personal support systems.

**c. Support**

- Building confidence and capacity, including by practicing the disclosure and subsequent conversations. This may involve support in writing and verbal communication skills;
- Connecting PHAs to Peers and/or networks specifically related to disclosure decisions;
- Identifying potential support and/or referral information for those being disclosed to;

- Ensuring follow-up and support after the disclosure discussion.

**d. Safety**

- Reviewing possible responses and creating a safety plan;
- Identifying possible referrals and resources.

**4. Application of Program Standards & Principles**

In making this policy work, and work consistently across the organization, we are committed to applying standards and principles in the following areas:

**a. Communication**

- Through our programming we will contribute to communicating the complexity of disclosure decisions and actions. This might be through the provision of legal information materials and will not include legal advice.
- All staff will be able to articulate the agency position and principles.
- The Teresa Group communication will contribute to a recognizable agency culture that might prompt discussions and a sense of safety for clients in relation to HIV disclosure.
- The Executive Director will be notified immediately of potential controversial or politically contentious situations relating to HIV disclosure as they relate to employees, service users and volunteers—or of community events related to HIV disclosure that will affect the organization and its clients. The Executive Director will be the principal spokesperson for the agency.
- Staff, volunteers (including Board members) and students associated with the agency who wish to express personal views or opinions on this issue shall make it clear that their views are personal and in no way, the views of the agency.

**b. Service Integration & Points of Access**

Opportunities should be sought within The Teresa Group programming to:

- Name disclosure as an issue for which the agency provides support;
- Communicate agency policy;
- Respond to inquiries and requests with appropriate information, referrals and access to support.

While all agency staff, volunteers and students can be potential points of access, the following particular opportunities exist:

- During Intake;
- Through general client check-in or re-assessment conversations;
- While accessing practical assistance programming; and
- As part of support services.

**c. Training Goals**

- All training participants will have found the training to be a safe place in which to discuss and learn the agency's position, and its rationale.
- Staff, volunteers (including Board members) and students will be able to articulate the agency position and be skilled in using the policy to increase knowledge of the complexities of HIV disclosure within, and external to the agency.
- Newly oriented staff, volunteers (including Board members) and students will clearly understand the agency's expectations regarding their duties of confidentiality and privacy of client information, and the limits, if any, of these duties. Staff belonging to regulated professions will also be clear as to the expectations of them.
- Additional training, specific to legal issues related to HIV disclosure will be regularly offered by HALCO.

**d. Monitoring and Evaluation**

The organization will monitor and evaluate its capacity and expertise in supporting clients in HIV disclosure decisions.

**e. Legal Questions**

The Teresa Group staff will proactively refer all legal questions and discussions to appropriate partners such as the HIV & AIDS Legal Clinic Ontario (HALCO).

Employees and volunteers will not give legal advice to clients, nor will they give personal opinions regarding any related circumstance surrounding HIV disclosure or the overly broad criminalization of HIV non-disclosure.

The Teresa Group will have an identified lawyer, familiar with the agency and disclosure issues, to provide appropriate support and opinions should the need arise.

**f. Trauma Informed Response**

The Teresa Group will support staff to be informed of their roles - including their role in making appropriate referrals - when responding to disclosures of trauma that may emerge in the course of HIV disclosure decisions and actions.

**g. Staff, Volunteer & Student Disclosure, and its Effect on Clients**

The Teresa Group is committed to managing the effect of staff, volunteer and student HIV disclosures on our programming. In so doing, we have a primary organizational duty to clients, while upholding the principles of GIPA/MEPA in supporting our staff, volunteers and students. The Teresa Group will:

- Ensure that staff, volunteers and students understand how the disclosure of their own HIV status could have unintended consequences for clients. Staff, volunteer and student disclosure of their own HIV status can contribute to creating a safe space, can increase peer connection related to the lived experience and can positively influence supporting the client. Staff

- disclosure can also, particularly where staff don't follow appropriate boundaries and share specific details of their HIV disclosure choices, either unintentionally burden the client, or unduly encourage them.
- Support staff, volunteers and students who choose not to share their HIV status with clients (including supporting Board members or volunteers to decide whether or not they wish to publicly represent the voice of PHAs/ the agency).

**h. Disclosure Dilemmas**

The Teresa Group will implement a concrete process to deal with ethical dilemmas that arise for staff around HIV disclosure issues—whether they are related to their own HIV disclosure, or client HIV disclosure. These are dilemmas where the rights and interests of two or more people are in conflict (perhaps two or more clients or two or more people known to the organization), or where an HIV disclosure situation presents two or more competing values or principles.

**i. Disclosures to Children**

There are special disclosure considerations related to children.

Some of the many unique circumstances that arise around children and family HIV disclosure include:

- There are increased points of vulnerability and loss of control during pregnancy process, which expand with increased access to the health care system;
- Disclosure questions and judgements related to infant feeding (“Is Formula Good for My Baby?” The Teresa Group & CATIE, 2015)
- Understanding child development and age-appropriate processes/messages/resources (“How Do I Tell My Kids”, The Teresa Group, 2009)
- Because of inconsistent responses within school systems, there can be significant fear that any family disclosure may negatively affect the school environment and result in possible discrimination;
- There is an increased risk of unintentional disclosure, particularly where disclosure has occurred with some but not all family members;
- Tensions between the HIV-positive parent’s right to confidentiality and a child or teenager’s need for support;
- Additional complexities and lack of control for children who are wards of the state;
- Inconsistent knowledge, interpretation, training and assumption and responses in other health and social service systems such as Children’s Aid Societies.

Children living with HIV: The Teresa Group will work closely with the family and with Sick Kids Hospital (or other relevant pediatric clinics engaged with the family) to support the gradual disclosure process to the child between the ages of 10 and 12 years.

Children not living with HIV themselves but living in a family affected by HIV: The Teresa Group offers some programs where mixed groups of children exist (some who have been disclosed to

and some who have not). In these programs, care will be taken to uphold confidentiality. If issues arise, staff will talk to disclosed children about the importance of confidentiality and will communicate with the parent(s).

Therapeutic groups run by The Teresa Group cannot accommodate children over the age of 10 years who have not been disclosed to about HIV in the family. Family Support Coordinators will discuss this with parents during intake and refer such children to other available programs and supports within the organisation or in other agencies.

Staff, volunteers and clients should always assume that children have not been disclosed to in order to avoid accidental disclosure.

The Teresa Group will offer training regarding this policy to all program partners whose staff may have contact with children in our programs.

#### **j. Record Keeping**

Record-keeping requires balancing the need to keep records with the desire to protect client confidentiality given the risks of data breaches and involuntary disclosures in the cases of search warrants and subpoenas.

Staff will discuss with the Program Manager anytime there is uncertainty of the level of detail or content to include in client records related to HIV disclosure.

The Teresa Group will develop procedures to minimize the amount of information that must be disclosed when issued with search warrants and subpoenas.

#### **k. Housing**

HIV disclosure can be significantly complicated by situations related to housing. Some of the unique considerations that The Teresa Group will be attentive to include:

- A PHA's residence: the disclosure of their address can precipitate unwanted disclosure or assumed disclosure from community or other tenants;
- Accessing supportive housing services: this may prompt disclosure or assumed disclosure;
- That HIV status disclosure is required for Priority Status Access to municipal housing;
- That some shelter system policies and practices (such as handing in medications to shelter staff) structurally force disclosure;
- That physical altercations where one or more tenants is a known client (or staff/volunteer/student) may result in police investigations and questions for the The Teresa Group.
- Long-term care facilities and appropriate training and support related to HIV disclosure of residents, particularly where dementia is a complicating factor;
- Staff will develop strategies to best support clients to maintain control of their disclosure decisions as we assist them in their efforts to be better housed.

#### **5. Related Policy & Procedure Review**

The following related Policies & Procedures will be periodically reviewed to ensure that they are consistent with this policy:

- Client record keeping;
- Confidentiality;
- Human Resource policies related to disclosure decisions of HIV+ staff in the work environment, in public, or on social media;
- Volunteer policies related to HIV+ volunteers;
- GIPA/MEPA policies.