

Appendix IV

- **AIDS Bereavement Project Background and Description**



AIDS Bereavement Project of Ontario

Background and Description of AIDS Bereavement Project of Ontario

Mission statement: *The AIDS Bereavement Project of Ontario is a resource to assist Ontario community-based AIDS organizations in enhancing their responses to bereavement through support, training, research and collaboration.*

The AIDS Bereavement Project (ABPO) provides community-based AIDS agencies with concrete support in the area of AIDS grief and loss. Funded by Ontario's Ministry of Health, the Project is a unique resource for Ontario groups wishing to look explicitly at AIDS-related grief and loss within their organizational settings. ABPO was formed in 1994 in response to a needs assessment conducted with 80 front-line staff and 13 Executive Directors and key managers who strongly identified multiple loss as an unaddressed issue requiring a coordinated, provincial response. The AIDS Bureau took up the challenge by providing funding for this innovative resource.

Background: The roots of the ABPO can be found in a 1990 AIDS Bereavement Program funded by ACAP and sponsored by the AIDS Committee of Toronto. That 3 year ACT-specific program developed structured, formal bereavement interventions for 5 distinct groups of people affected by HIV who were linked as clients or workers with the agency:

- caregivers (professional and volunteer)
- lovers of people with AIDS
- family: parents, grandparents, spouses, children, siblings
- friends of people with AIDS
- people living with HIV/AIDS

A series of short-term, closed, 8-10 week bereavement groups were offered for these populations and a formal training for facilitators was conducted by professionals from Bereaved Families of Ontario. As the final report of this project demonstrated, one of the obstacles to delivering ongoing bereavement programs to community and clients was the lack of structured supports for the staff and volunteers designated to facilitate these groups. The lesson was clear: agency personnel require their own mechanisms for attending to the effects of

multiple loss experienced through the course of their work. Because AIDS workers were also bereaved themselves, they required additional supports, skills and training to work with a grieving clientele.

ABPO is mandated to provide these caregivers in Ontario's ASOs with the tools to respond effectively, at both an individual and agency level, to the unique grief arising from the AIDS deaths of clients, colleagues and friends. With the changing nature of HIV disease, agency personnel are relating to AIDS as an illness increasingly associated with unpredictability, uncertainty and anticipatory grief in addition to the pre-existing legacy of multiple losses. Increasingly staff and Board are called on to expand their creative responses to include agency shifts in strategic directions resulting from changes in client demographics and funding challenges. The Bereavement Project works with groups to design workshops, train paid and unpaid workers and assist management in assessing and enhancing individual and agency coping strategies related to loss and transition of many types.

It is the experience of ABPO staff, born out by an evaluation of the project conducted in 1997 (Gibson & Plotnick), that a solid theoretical framework for grief and an appreciation of the complexity of the ensuring "journey of loss" can provide workers with vital competencies for better managing changes associated with HIV and with the realities of organizational life in an AIDS agency.

Structure

A strategic and cost-saving decision was made early during the conceptualizing of the AIDS Bereavement Project to "administratively house" the Project's 2 staff and occasional contract workers within a larger, stable ASO rather than establish the project as an independent incorporated organization. After successful negotiations, ABPO has been under the umbrella of Fife House Foundation, Inc. since 1994. All funds for the ABPO are administered through Fife House. Program areas are guided by ABPO's provincial Advisory Board.

Advisory Board

Overseeing the AIDS Bereavement Project is a wise, dedicated and passionate Advisory Board representing an excellent diversity of ASO workers and professionals from bereavement, hospice and community development sectors, in addition to PHAs and bereaved community members.

Meaningful participation of People living with HIV/AIDS (PHAs)

People with HIV have helped shape, create, deliver, assess and monitor ABPO activities since our inception. Key Advisory Board members who identify as PHAs and are invited to participate in program activities in a consulting capacity as requested by client groups.

Community involvement

Evaluations from the hundreds of workshops facilitated by ABPO staff provide continuing feedback from our clients regarding our relevance and effectiveness. In addition, a formal evaluation was conducted in 1997 assessing the impact of AIDS related multiple loss on the ASOs in the province and evaluating the impact of the AIDS Bereavement Project's programs: consultation, educational seminars, experiential grief workshops. The report, The AIDS Bereavement Project of Ontario: Program Evaluation by S. Gibson, PhD. and A. Plotnick, PhD., 1997 is available from the APBO office. The central evaluation conclusion was: *"AIDS service organizations can indeed be characterized as "grief agencies" wherein the personnel, staff, management, Board and volunteers are saturated with grief as they are working in communities also struggling with bereavement overload. Multiple loss appears to have had both a positive and negative impact on individuals and on their organizations. The vast majority of individuals surveyed and interviewed emphasized the importance, usefulness and the need for the ABPO in assisting them to cope more effectively and creatively with ongoing and multiple losses."*

Catchment Area: We are mandated to provide services to ASOs and community agencies with an HIV component within the province of Ontario

ABPO Program Components and Activities:

To summarize, the main areas of activities for ABPO can be described as:

a) Grief –related Information and Research:

- To collect, review, organize and disseminate relevant materials pertaining to AIDS-related loss and the impact on our workers, communities and organizations. This includes documenting our activities, analyzing data from evaluations and preparing the information in a form useful to ASOs.
- To be a focus for research on the topic of AIDS-related multiple loss.

b) Facilitation of Workshops:

- To work with ASO managers to assess impact of loss on agency personnel and workplace teams and from there, to create an intervention strategy that enhances the ability of workers to respond effectively to loss while building an agency culture consistent with Board and management vision.
- To design and deliver agency-wide interventions for paid and unpaid AIDS workers dealing with the effects of ongoing multiple loss and community devastation. These workshops are usually 1-2 days in length and

generally work with staff teams separately from Boards and volunteer groups.

- To develop a range of bereavement interventions utilizing adult education models designed to reach the person at both the cognitive and affective level so that material presented becomes better integrated into theory and practise.
- To assist agencies in developing a range of practical strategies to meet the needs of staff and volunteers facing loss and of community members dealing with grief.
- To work with agency managers to develop tools for sustained resiliency within their organizations as workers deal with ongoing loss and manage change and transition.

c) General Education:

- to present on matters of AIDS loss and impact on workers and agencies through various workshops and conferences
- to make our print materials available through networks such as the national HIV/AIDS Clearinghouse
- to respond to media requests related to matters pertaining to our mandate and activities

d) Training:

- to develop training programs on AIDS bereavement targeted to specific needs of agencies and workers in the province
- to deliver training programs to several distinct levels:
 - * staff and volunteers, who work directly with grieving clients;
 - * educators, as they integrate an awareness of the impact of loss into their health promotion and harm reduction campaigns;
 - * managers, who supervise workers dealing with present, past or anticipated loss;
 - * and towards program coordinators and managers, as they create a team and organizational culture that acknowledges loss and responds effectively to the challenges presented by death and ongoing change.

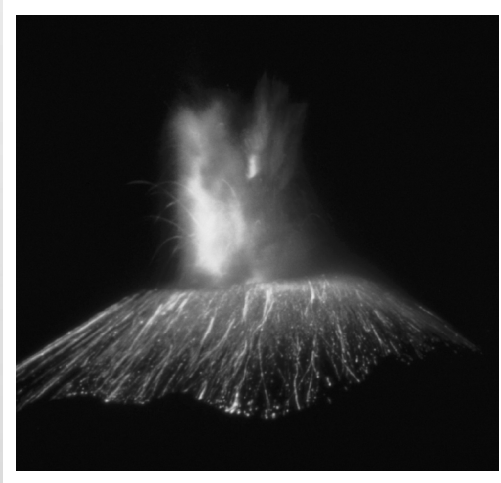
- to prepare written materials that will accompany these training programs and be available as resources for agencies sustaining this work in their communities

e) Consultation/Resource Provision/Collaboration:

- to develop a resource list of bereavement referrals within the province for agency personnel requiring additional information or support
- to provide access to our extensive literature reviews as workers seek out grief and trauma-related information
- to be a resource for agency personnel requiring specific problem-solving related to service delivery or human resource matters shaped by loss
- to work with AIDS networks and resources such as the OAN, CAS, and the Organizational Development Program as well as bereavement, long-term care services in the community and hospice networks
- to act as a resource for AIDS organizations developing grief programs as part of their services (provincially, nationally and internationally)

From January 1994 to December 2002, ABPO staff facilitated 350 workshops for 214 agencies reaching 3496 workers; developed and delivered 38 training programs to 873 agency personnel and presented at 113 conferences to 7,120 participants. Conferences include 3 International AIDS Conferences and a variety of national and provincial events. Consultations were not counted, but were numerous. ABPO is indeed proving to be a unique resource not only in Ontario, but also in Canada.

Through the activities of these past 8 years of operation, ABPO has gathered information on the specific bereavement needs and responses of individuals working in ASO's. We have developed relevant assessment tools and present theory and language of multiple loss in a practical format. We have designed and delivered structured, time-limited bereavement interventions through a 1-2 day workshop format and have consolidated our data into targeted training programs for ASO workers. We have produced 2 training manuals to accompany these trainings and are currently co-producing a 3rd for facilitators and managers. We have brought in researchers to help us evaluate the effectiveness of our interventions and to prepare more formal documentation of the impact of ongoing loss in agency and community contexts. ABPO information has been successfully brought to AIDS workers, community activists and funders at provincial, national and international levels.



Appendix V

- **Reading List**
- **Comprehensive Literature Review**
- **Video and Web Site List**

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Comprehensive Literature Review

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Topic Areas:

- ◆ AIDS Bereavement
- ◆ AIDS-related Multiple Loss
- ◆ ASOs and Grief
- ◆ ASO History and Challenges
- ◆ Bereavement and Grief Theory
- ◆ Caregivers and Burnout
- ◆ Counselling and Countertransference
- ◆ Cross-Cultural Grief and HIV Issues within Diverse Cultural Communities
- ◆ Professional Comfort and Skill Development in Working with HIV
- ◆ Research
- ◆ Trauma, Disaster, Stress & Coping
- ◆ Women and HIV

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Longtime Companion. 1989. 90 min.

Male Couples Facing AIDS. 1988. 30 min.

RSVP. 1991. 23 min.

Thinking About Death. 1991. 29 min.

This Is Dedicated. 1992. 24 min.

This Is My Garden. 1990. 26 min.

Too Little, Too Late: Families

of AIDS Patients. 1987 48 min

Ideas on Camera (CBC)

American Playhouse

Focus International

Miracle Film (Toronto)

Gay Men's Health Crisis (NY)

Alleycat Productions (Dist. by Filmmakers Library)

Alex Benedict (Dist. by Filmmakers Library)

Fanlight Productions

(Dist. by Canadian Learning)

www.bereavement.org

www.denning.ca/grief.htm

www.icomm.ca/ccvt/index.html

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