PROJECT SUSTAIN

Creating and Reinforcing Organizational Supports for ASO Workers Coping with the Impact of Multiple Losses

Final Report

February, 1999 – March, 2002

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AIDS Bereavement Project of Ontario

Forward

We are pleased to bring you the _Project SUSTAIN Final Report for 1999-2002_

Project Sustain was initiated in 1999 as a means to create and reinforce organizational supports for AIDS workers coping with the impact of ongoing multiple loss. At that time, the sponsoring agency, the AIDS Bereavement Project of Ontario (ABPO) had been in existence for 5 years, serving as a resource to assist community-based AIDS service organizations (ASOs) in enhancing their response to loss, change and transition. ABPO had gathered much information on the specific bereavement needs and responses of staff and volunteers working in both urban and rural settings. Their project evaluations confirmed that their interventions and materials provide workers with the individual and organizational supports vital to assist them in maintaining their spirit and resiliency in this tough field.

In 1999, ABPO was challenged by several key AIDS agencies in other parts of the country to develop a framework to respond to the loss needs of workers in ASOs outside of Ontario. In meeting this challenge, ABPO supported the creation of Project Sustain, a 3-year national pilot project designed to quantify and describe the impact of AIDS grief, provide regional comparison of the unique challenges facing ASOs, and identify and help initiate resilient strategies within ASOs in three distinct regional settings: Vancouver, Winnipeg and the Atlantic. Project Sustain staff and Regional Resource People designed and delivered 45 workshops for 350 participants in 20 pilot sites across 3 regions of this country. We trained 14 Regional Resource People and are left with solid data about AIDS-related loss and resiliency. You can find out more about the theory, research tools and results of this exciting and inspiring work by reading through this report.

We are deeply appreciative of the work and passionate dedication of our evaluator, Val Gervais from Edmonton. Her commitment to making the research findings come alive has created a relevant body of knowledge about AIDS work and loss and has birthed exciting tools such as the Resiliency Map. We are grateful as well to all those who pushed us and worked with us across many regional differences to make Project Sustain come alive. We anticipate further national endeavours as the concepts of worker resiliency distilled through Project Sustain continue to be developed by Regional Resource People committed to this work.

We invite you to also take a look at the companion document to this report, _Project Sustain Basics of Grief and Multiple Loss a Training Manual for AIDS Service Organizations_. The Training Manual provides a thoroughly tested "how- to" manual accompanied by solid, relevant background material on AIDS-related multiple loss. We see this as an evolving body of work. We are currently developing training materials that incorporate the loss framework described in this Training Manual as the basis for working with the complexities of organizational change and transitions.

And a note of gratitude to all those who live with HIV and AIDS, who teach us every day through their grace, stubbornness and determination, to those who come to work in our community-based ASOs- the work is tough and surprising every day. And to those who have died of AIDS, our commitment to their legacy is at the very heart of all this work. We lean into the pain of loss so their stories can continue to have meaning and their spirits can help us remember to sing with the gift of life.

Yvette Perreault

*The **Resiliency Map** was created through the experience of the*

***AIDS Bereavement Project of Ontario's Project Sustain**,*

a 3-year national project designed to

"identify the impact of AIDS grief and multiple loss,

provide regional comparison of the unique challenges facing ASOs,

and attempt to identify and help initiate strategies for resiliency,

within three distinct regional AIDS Service Organizations

in Vancouver, Winnipeg and the Atlantic."

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I. Project SUSTAIN Executive Summary

(a) Why Grief and Loss and AIDS Service Organizations?

- Grief and Loss is central to worker's experience in coping with HIV
- ASO clients and caregivers (personal and professional) are experiencing multiple losses, disenfranchised grief and complicated mourning
- ASOs are experiencing the negative impact of multiple losses resulting in:
  - decreased organizational functioning
  - impaired communication
  - decreased organizational capacity outside ASO
  - decreased capacity to maintain skilled staff (due to emotional exhaustion) within ASOs.
- These challenges are continuing to occur within ASOs at a time when ASOs are coping with transition, reduced funding, and more complex and diverse client populations.

Why Project SUSTAIN?

- *Canadian Evidence*
  - Cain (1993, 1994,1995, 1997) documenting the history and challenges of ASOs.
  - AIDS Bereavement Project of Ontario Evaluation (Gibson & Plotnick, 1997)
  - Gervais (1998) Multiple Loss qualitative study within an ASO
- *Negative Impact on Organizational Functioning and Mental Health documented (AIDS Bereavement Project of Ontario (ABPO), Gervais)*
- *Creative Coping Strategies observed in a climate of AIDS Multiple Losses within an ASO (Gervais)*
- *Organizational Interventions to assist in healing losses assist with resiliency (ABPO)*

(b) Project SUSTAIN Key Components

Purpose: Creating and Reinforcing Organizational Supports for ASO Workers Coping with the Impact of Multiple Losses

Collaboration:

- AIDS Bereavement Project of Ontario & Researcher
- National SUSTAIN Task Force
- Working with 20 ASOs in Three Regions (primarily Vancouver, Winnipeg, Halifax-Atlantic) of Canada over three years to mentor Regional Resource People and provide intervention materials.
- ACAP, Health Canada & MOH Ontario

Regional Resource People and ASO Pilot Sites' Listing:

Atlantic Sites:	**Regional Resources:**
AIDS Coalition of Cape Breton	Connor Loomis
AIDS Coalition of Nova Scotia	Roy Ellis
Healing Our Nations	
Mainline Needle Exchange	
Stepping Stone	
Winnipeg Sites:	
Nine Circles (previously)	Velma Orvis
Manitoba Aboriginal AIDS Task Force	Marion Gracey
Village Clinic	
Kali-Shiva	
Manitoba Housing Action	
Winnipeg Regional Health Authority	
Vancouver Sites:	
AIDS Vancouver	Geoff Straw
Friends for Life	Shayna Hornstein
Lovin' Spoonful	John Dube
Positive Women's Network	
YouthCo	
Chee Mamuk	
West Coast Pediatric AIDS Society	
Healing Our Spirit	
Vancouver Area Network of Drug Users (VANDU)	
Storefront Orientation Services (SOS)	

Activities>>>

1. **TASK:** Develop tools of assessment unique to ASO culture.
   (February 1999 – April 2000)

   RESULT: Quantitative and Qualitative assessment and comparison of multiple loss, organizational transition, and methods of resiliency within ASOs in 3 regions in the country. Education regarding grief and organizational transition to staff and boards.

2. **TASK:** Develop and document intervention tools of support and healing.
   (February 1999 – present)

   RESULT: Provide direct ASO organizational support through education and facilitation with individuals, staff groups, administration (executive and board members), and community organizations. Individual and Group Interventions assist with identification of impact of losses and to begin to build grief maintenance strategies

3. **TASK:** Develop strategy for sustained resiliency.
   (April 2001 – March 2002)

   RESULT: Follow-up planning, local resource identification and development. Training and support to local resource people from 4 regions in Canada. Consolidation of training resources, including the manual, **The Basics of Grief and Loss: a Training Manual for ASOs**.

   (i) Development of Individual and Group Grief Assessment Tools

   - What Sustains Workers? - Questionnaire
   - Assessing Impact of Loss
   - Organizational Assessment Questionnaire
   - Loss History Questionnaire
   - Body Map
   - Shifts in the Work

   (ii) Building Criteria for Organizational Grief and Loss Facilitators: Known as Regional Resource People

   - Self-Awareness: Facilitator Questionnaire
   - Knowledge of grief, multiple loss, facilitation, community-based organizations.
   - Skills for integrating a holistic framework into both individual and organizational work.
   - Ability to develop interventions which identify and mitigate grief stressors and address depletion of workers

Project SUSTAIN Activity and Evaluation Data Summary
February 1999 – March 2002

TYPE OF ACTIVITY	VANCOUVER	WINNIPEG	ATLANTIC	TOTAL
Workshop – Feb 1999 – Spring 2000				
• Number of workshops	21	6	6	33
• Number of participants (Includes participants who participated in more than one workshop)	193+ (participants from the closure workshops for each visit are missing from this total)	103	44	340+
Number of Individual Consultations - Feb 1999 – Spring 2000 (on the regional site with Project Facilitators)	37	-	5	42
Meetings/Consultations Feb, 1999 – Spring, 2000 with				
• ASO Management	4	2	4	10
• Local Resource Person	14	-	4	18
• ASO Board	1	1	2	4
• Funders	-	-	1	1
• Community Group	3	1	1	5
Resources – Feb, 1999 – Spring, 2002	• Tool Kits for Each Region	• Training and Mentoring Regional Resource People	• Facilitator Training Manual	
Regional Resource Person Agency Sessions: 2001 – Spring, 2002	24	5	16	45
Evaluation Data & Activities				
• What Sustains Workers? - Survey Questionnaire – Fall, 1999	9	10	8	27
• Ethnographic Case Notes or Visit Summaries from Project SUSTAIN Facilitator Regional Activities – 1999 to 2001	3	3	3	9
• Evaluation Questionnaire – 2000	2	6	5	13

	Ontario	Vancouver	Winnipeg	Atlantic	Total
• Project SUSTAIN Regional Resources Person Facilitator Training Pre-Assessment Questionnaire – Fall, 2001	8	2	2	2	14
• Project SUSTAIN Post-Training I Evaluation Questionnaires – Fall 2001 (Two types of evaluation questionnaires were used.)	6	4	4	1	15
• Project SUSTAIN Facilitator Training I Participants– September 19-22, 2001	8	2	2	1	13
• Project SUSTAIN Facilitator Training II Participants - April 4-6, 2002	8	2	2	2	14
• Session Records from Regional Resource Person Activities – October, 2001 – March, 2002	-	10	1	6	17
• Project SUSTAIN Post - Training II Evaluation Questionnaires – Spring 2002	• 12 Evaluations across the regions				

Project SUSTAIN Research Findings: ASO Workers

ASO workers across Canada are:

- Coping with complicated grief characterized by unresolved personal, professional and organizational losses because of AIDS grief and multiple loss. Physically and socially experiencing isolation.
- Experiencing fatigue and inadequate sleep as a primary symptom identified with grief.
- Experiencing physical pain, especially headaches and back/neck pain.
- Exacerbating these problems by overworking as a coping strategy to avoid/cope with grief or deal with the endless demands where insufficient resources exist.

ASO workers across Canada report the Emotional Impact of grief and the energy demands of AIDS Work result in:

- Sadness or Depression
- Numbness
- Anxiety
- Anger
- Tearfulness

Project SUSTAIN Research Findings: ASOs

ASO Organizational characteristics:

- Staff Turnover and Burnout
- Irritability
- Emotional Outbursts
- Co-workers are not used as frequently as expected
- Grief has a negative impact on care and communication within an ASO
- Denial of or unaware of impact of grief

ASO Workers are coping with **Additional Organizational Challenges:**

- Uncertain program planning due to the fast changing, diverse, and non-homogeneous client population.
- Ambivalent commitment of volunteers.
- Uncertain provincial support and financial and skilled personnel resources.
- Perpetual state of crisis while needs are more complex and diverse.

ASO Differences across regions:

- Organizational size and current organizational and community challenges
- Age and years of experience of workers
- Primary population they were serving
- Extent the organization was able or ready to create a strategic plan and locate resource people in their own communities

Project Sustain Overall Recommendations

- ASO grief strategies need to be organizationally, community and culturally specific
- Reduce the impaired communication patterns within ASOs
- Create and maintain a healthy understanding and climate for the sharing of grief
- Encourage and support creativity and a healthy, balanced commitment to the work
- Advocacy to secure funding to address and highlight the unique organizational and grief challenges
- Future national collaboration and education or training
- Development of organizational grief resource manual
- Future research

(c) Impact of Multiple Loss on Individuals and ASOs

AIDS-related Definition of Multiple Loss:

Insufficient time to grieve before the next loss occurs creating:

- *Chronic and Compounded Grief*
- *Bereavement Overload*
- *Death Imprint*

Negative Impact of HIV-related Multiple Loss

Experience of negative impact on Mental Health, including:

- Increased Emotional Distress – Anxiety, and Anger, Survivor Guilt
- Depression, Suicidal Ideation, Sedative Use
- Increased Social Isolation & Social Stigma, and Reduction of Social Support
- Long Term Irreparable Effects on Mental Health
- Catastrophic Thinking & Change in World View

Positive Impact of HIV-related Multiple Loss

- Adaptation to Multiple Loss is observed.
- Creative Coping Strategies are identified.
- Bereaved and Professionals working in a climate of multiple loss are known to be 'Resilient'.

Resiliency to HIV-related Multiple Loss

Characteristic of Multiple Loss Bereaved:

⇒ Find "meaning in their experience which helps honor their losses".

⇒ Experience "self discovery and personal growth", especially spiritual growth.

⇒ Discover the "importance of interpersonal relationships".

⇒ Known to have a "cyclical process of coping" by creatively investing their feelings into actions when there is insufficient time to grieve.

⇒ Need to "build social supports" and "relate with at least one other person who has the lived experience" of coping with multiple loss.

Key Behaviours:

⇒ Ongoing and Consistent Self Care

⇒ Boundary Setting – Limit Activities and Roles that Provide Exposure to Multiple Loss

⇒ Limiting or Being Selective in One's Participation in Grief Rituals

⇒ Temporary to Permanent Forms of Emotional and Physical Distancing

⇒ Bereaved achieve resiliency by focusing on coping strategies of:

- "Optimism"
- "Active Problem Solving"
- "Positive Reappraisal"

Community Elements:

⇒ 'Social Activism and volunteerism' has helped both bereaved and professionals working with multiple loss find meaning in their experience

⇒ "Personal and Community Rituals" assist in transforming the multiple losses.

(d) The Evolving Theory Base

- ▷ Single Loss Theories
- ▷ Disenfranchised & Complicated Grief Concepts
- ▷ Trauma, Disaster, Stress & Coping Literature
- ▷ Social, Political and Cultural Context of HIV
- ▷ Multiple Loss Frameworks

Single Loss Grief Theory

Grief is our response to a perceived or anticipated loss that can result in a challenge to develop a new identity and view of our reality. There are a variety of terms and definitions used to describe grief. There is also differing opinion on the period it takes to grieve with some believing grief is time limited and others believing it is a limitless life long process (Rodger & Cowles, 1991).

Grief affects our physical, social, cognitive, affective, behavioral, and spiritual self. As individuals we are often totally unaware of the complexity and normalness of our responses to grief. We often think we are abnormal, out of control, or going crazy at the time when we are experiencing tremendous responses to a loss. Knowledge and education about the absolute normalness of our grief responses gives us a sense of control, and helps us ride the waves of grief responses.

Critique of Single Loss Grief Theory:
It does not account for:

- Complicated Mourning
- Multiple Losses
- Social, Political and Cultural Context of HIV

Disenfranchised Grief:

- Grief that is not or cannot be openly acknowledged, publicly mourned or socially supported.
- It complicates grief by reducing access to social supports or excluding mourners from roles that will assist with mourning.
- It creates an intensifying of emotional reactions such as anger, guilt, and powerlessness.

Complicated Grief:

- Helps explain why an individual has not adjusted to a particular loss.
- They are various types of complicated grief and various terms used to describe complicated grief.
- Is related to the intensity or duration of a reaction.

Factors Associated with the Development of Complicated Bereavement:

> Judgmentalness about the grieving process.
> Lack of support from significant others and/or the community.
> Past unresolved grief that influences the reaction to the current loss.
> Restrictive values or beliefs about loss and/or grief.
> Physiological or psychological illness.
> Lack of information about normal grief.

(e) Tasks and Challenges for Caregivers and ASOs

<u>Awareness</u>

- Recognize that multiple loss bereaved may have a more familiar, intimate and comfortable relationship with dying and the dead than with the living
- Recognize that the central challenge for bereaved is to balance the pain of loss with hope and commitment
- Normalize the experience of the bereaved and educate them about grief and multiple loss
- Focus on current loss and assist bereaved in discovering the complex layering of multiple losses

<u>Support</u>

- Encourage peer support, personal and community rituals of healing.
- Help Bereaved link the loss to the social and political factors that have contributed to the pain (e.g. Social Injustice, Stigma, Discrimination, Social Isolation)
- Explore Social Activism and Volunteerism with the bereaved which may help them invest their complicated feelings and experiences into meaningful activity
- Assist bereaved in discovering:
  - Areas of personal growth and discovery created by their experiences with multiple loss
  - Identify Self Care Strategies, Boundaries and Limit Setting
  - Creative personal coping strategies which emphasize optimism, active problem solving and positive reappraisal

(f) <u>Tools for Loss Assessment and Resiliency</u>

- Organizational Strategies
- Grief Assessment Cone (see page 28) to help examine the interconnected, complex layering that occurs with Multiple Loss -
  - Red Oval – The personal grief and losses
  - Blue Oval – The Emotions & Coping Processes
  - Green Oval – The Family and Community Resources
  - Black Oval – The Social, Political and Cultural Context which contributes social Injustice & isolation, stigma, and discrimination
- Regional Resource Facilitators
- Training Sessions and Manual

II. Project SUSTAIN Task Force

(a) Project SUSTAIN Task Force Member List

March, 2002

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II. Project SUSTAIN Task Force Recommendations

Task Force had a full 2-day meeting in Toronto, which happened March 8 & 9, 2002. It included a full review of regional pilot site activities and an in-depth discussion from the representatives of the three original pilot sites, AIDS Coalition of Nova Scotia, Nine Circles (previously Village Clinic) and AIDS Vancouver. Support for the continued training of Regional Resource People was unanimous, as well interest in future work at national level.

Significant components of the discussion included a presentation and group exercise lead by Val Gervais of the group exercise tool, the Resiliency Map. All members of the Task Force felt strongly that this tool would assist them not only in their agencies, but also in their regions.

All had concrete gains to report from the work of Resource People, though each region has continued to design and implement interventions in unique ways. For example, in Winnipeg, Nine Circles is having successful one-day retreats for all staff off-site and is planning another for the spring. Whereas, in Vancouver, at YouthCo, small staff groupings met for staff support and de-briefing. All regions wanted to explore mechanisms to continue work with the Regional Resource People and to increase availability to other ASOs in their regions.

Members are committed to continuing to work together on an on-going basis, as the SUSTAIN Task Force. The primary focus for the coming year will be to continue to support ASO worker resiliency through five main objectives:

1. **Creating a national mechanism,** so that Regional Resource People have both resources and an infrastructure to support them, in terms of further mentoring, and additional training to build their skill base to support others.

2. **Documentation of SUSTAIN work** as it contributes to models of healthy organizations and leadership, for use directly in pilot ASOs, and in regions which have not yet participated in this work.

3. **Continuing to work in collaboration with the various strengths of the pilot regions**, including:
   a) policy development and organizational wellness strategies being developed with support from AIDS Vancouver in British Columbia
   b) integration of Aboriginal healing models and techniques being supported from Winnipeg and Ontario Resource People
   c) addressing rural and urban ASO issues and also international development issues with the experience base from ACNS in Nova Scotia
   d) incorporation of new tools and knowledge from ABPO's long-term PHA project

4. **Exploring opportunities for community-based research** to test out the Resiliency Map and other SUSTAIN assessment and intervention tools, in order to gain wider recognition and validation.

5. Utilizing the previous listed activities, **to build a broader committee to establish a formal gathering to present these finding to the national ASO community, i.e. 'National ASO Worker Resiliency Forum'.** This could become an initial component of launching SUSTAIN as a national strategy to include the provinces and territories not included in the pilot work.

These themes echoed Val Gervais' findings and recommendations from our Year One report, listed below, particularly the need for a coordinated effort to shift organizational patterns and create balance in the workplace, the need to secure funding to support the work and the need for further resource development and research.

III. Evaluation Reports

(a) FINAL Evaluation Report
Evaluator: Val Gervais MSW., BSW., RSW

Project Sustain began in February 1999 as a community development national project in response to the impact HIV disease has had on individual, organizational and community functioning. Three primary regions, Vancouver, Winnipeg, Halifax joined with the resources and practical experience of AIDS Bereavement Project of Ontario to create this project. This project, February 1999 to Spring 2002, has achieved four primary goals:

> ***i) Investigate the impact of multiple losses, disenfranchised grief and current transitions in HIV disease on AIDS workers and on their agency.***
> ***ii) Provide an initial assessment of worker and agency's current coping strategies related to loss.***
> ***iii) Develop a model for organizational interventions aimed at reducing grief-related stressors.***
> ***iv) Create a resource of relevant bereavement supports for the local AIDS Service Organizations in each of these regions.***

Documentation of the various elements of the project, including the Year One Evaluation Report and copies of tools mentioned are all available from the ABPO office with contact information on the cover of this report.

Impact of HIV-related Grief and Multiple Loss

This project identified that HIV workers across the country are challenged to cope with HIV disease. HIV workers are physically and emotionally exhausted, experiencing complicated grief and that has affected the care and communication and capacity for AIDS Service Organizations to respond to the ongoing challenges of HIV – related multiple losses. Organizationally there is staff turnover and burnout, often organizational denial or challenge to cope with the impact of HIV-related multiple loss. Organizations have been further challenged to create a response given the changing and more complex client populations, changing mandate, and organizational transitions. (See above section, Findings and Appendix III Year One Evaluation Report)

Project SUSTAIN Activities

Project SUSTAIN has demonstrated the benefits skilled facilitation has in mitigating against the negative impact of HIV-related multiple losses and organizational change. Extensive individual, organizational, and community interventions occurred, a thorough training manual was developed, and skilled Regional Resource People were identified

and trained during this project. Resilient coping strategies both for the individual, organization and community were identified. A holistic approach that incorporated the physical, mental, emotional, spiritual and community responses to grief were necessary to help mitigate against the challenges of HIV-related multiple losses. A combination of qualitative and quantitative approaches were used to evaluate this project, see table on page 7.

Training of Regional Resource People

A national training session was developed initially in September 2001 with 13 participants (8 Ontario, 2 Vancouver, 2 Winnipeg and 1 from Halifax). The training was evaluated by using pre and post training evaluation questionnaires, which were completed by Regional Resource People. We have discovered that extensive skills and training are required in order to be an effective Regional Resource Person to an ASO community. This skills base is needed given the cutting edge nature of the work and the chronic bereavement challenges within a constantly changing organizational community. We have also discovered that the nature of the work Project SUSTAIN has created is ground breaking both in theoretical development, and practical intervention.

Regional Resource People identify increased self-awareness of the holistic impact of grief following the training. They have increased awareness of the skills they offer, increased preparedness for working in a group, and increased awareness of the skills they will need to develop to assist with grief expression in their role as Regional Resource Person. Overall they had the greatest increased skill development in the areas of 'Grief' and 'ASOs'.

Regional Resource People had an opportunity to experience the holistic approaches to bereavement as represented by the grief cone theory and the holistic knowledge and healing approaches represented by the teachings and knowledge of aboriginal participants. The post training evaluations revealed that further training was recommended to provide Regional Resource People the opportunity to learn the group exercises and the grief theory in greater detail, and to have follow-up once they had the opportunity of testing their tools in each region. This follow-up was important to continue to provide support, education and supervision given the demands of this work, its complexities, and the cutting edge nature of Project SUSTAIN activities.

The cross-cultural learning and development of collaborative relationships was an unexpected outcome of this first training session. The necessity to foster this cross-cultural learning seems paramount given the growing HIV infection within aboriginal communities. Finally, an unintended outcome from these collaborative relationships lead to the development of the grief theory into a group exercise tool, the Resiliency Map. It is an integral part of the practical teaching and bereavement resource kit of Project SUSTAIN. (See Evaluator Report – December 2001)

The second Regional Resource training occurred April 2002 to allow for this further skill development. Fourteen Regional Resource People attended - 8 from Ontario, 2

Vancouver, 2 from Winnipeg, and 2 from Halifax. Thirteen evaluation questionnaires along with considerable verbal comments make up the reflective evaluation of this second training.

A Resiliency Map was made as an assessment and theory presentation tool and a full day of facilitation of its practical group approach occurred during this second training session. Participants describe this as a valuable regional tool that is powerfully integrative of theory and application. It assists with eliciting stories of relationship to AIDS work and with providing healing. Regional Resource People also describe seeing the benefit of its potential application in other settings. Regional Resource People were also given a Resiliency Map for each region as part of their Regional Resource kits.

The contribution of aboriginal holistic healing approaches was an evolving skill regional resource participants experienced during this training. ***This holistic approach, and particularly the knowledge of Diane Hill on the Unburdening Process, was viewed to be a necessary holistic skill, by Regional Resource People in expanding their holistic approaches to healing grief and multiple loss.*** Diane did not have sufficient time to present her work, though most had the opportunity to at least witness its' application in September, but we had insufficient time to discuss its application.

There is also a necessity for ongoing discussion on the historic and emerging voices and challenges HIV creates. Regional Resource People found Derek Scott's facilitated discussion very helpful in this regard. Potential other skills in the future might also incorporate bodywork. Regional Resource People describe the effectiveness of building our personal capacities as healers in order to be an effective Regional Resource Person. They identify with working in a group setting and practical learning model. Opportunity to lead in collaborative facilitation would further develop the skills of becoming a Regional Resource Person. Regional Resource People identified the need for intermittent reflection/ training once or twice a year, and access and distribution of current theoretical and practical materials.

Regional Resource Person Activities

Regional Resource People participated in 45 Agency sessions, 25 in Vancouver, 5 in Winnipeg, and 16 in the Atlantic. We have received 17 session reports from those activities. They represent the fundamental need for the development of collaborative relationships, especially with the organizational leadership, in order to help prepare the environment for coordinating interventions. Resource people describe the usefulness of current tool kit resources provided by Project SUSTAIN. The activities have incorporated education about loss and grief, coping strategies, and activities to develop personal reflection/ further skill development in response to the impact loss and grief has on the individual and organization. These reports represent the necessity of creating a safe container and capacity to do the work. Aboriginal teachings and opportunities to nurture spiritual growth were also used. Spiritual growth was identified early on in the initial findings as a consistent strategy that assisted with resiliency.

Summary and Future Strategies

This national project has created effective strategies to mitigate against the chronic bereavement and organizational challenges experienced by ASOs and their workers. We have expanded our knowledge of the effective training approaches necessary to do this work. We have tools to help create and maintain positive social environments, and assist organizations in a process of transition. Organizational strategies for wellness and recommendations for policy development to help maintain resilient workers are known.

Inherent in this work has been a willingness and necessity to do community development and build partner agencies. The activities of building broader community understanding of grief and multiple loss and developing effective strategies with collaborative partners has been a healthy resilient strategy. We have had a beginning experience of collaboration with Aboriginal Community as a result of our project activities. This cross-cultural learning would assist with learning holistic approaches to grief, multiple loss and healing and further our skill development in response to the increasing HIV infection within Aboriginal community.

There are opportunities for collaborative learning by applying Project SUSTAIN activities to assist Residential Housing programs to also develop resilient strategies. This project has been primarily situated within an urban community. The current urban project sites could play a significant role in mentoring and supporting their rural partner agencies and discovering the differences in rural and urban experience. The project has had some involvement with Collaboration with International Community Development. Workers from India and now South Africa have identified the significant contributions Project SUSTAIN work will have in their communities.

What remains is to maintain and further the development of these skilled facilitators and to expand these skills and resources to other partner provinces and international communities. We have learned from this project that Regional Resource People must be highly skilled entering the work and yet they require further skill development particularly in the area of grief, ASO knowledge and group intervention. As Project SUSTAIN activities become recognized as significant contributions to the ASO movement, the means to distribute and maintain this information also become necessary. Ongoing training, literature reviews, web site resources, and conference participation are seen to be vital tools for this development aspect of the work.

Page 6 contains the Project SUSTAIN Activity and Evaluation Data Summary February, 1999 – Spring, 2002. As noted in section a), through reflections on gaps between actual implementation and the original workplan, this data does not include the numerous emails, phone calls, and activities within each region that carried the momentum of this project between Project SUSTAIN facilitator visits.

(b) Year Two: *"Building on our personal and theoretical history"*

The ongoing organizational data for this year continues to confirm and enhance our knowledge of the findings and impact that HIV-related loss has on ASOs. The ethnographic research of Project Sustain continues to build on a foundation of knowledge within Canada that began with Gibson & Plotnick (1997) work through in its evaluation of the AIDS Bereavement Project of Ontario. Gervais' (1998) in-depth qualitative analysis highlighted the complex multi-layered grief themes within a Canadian ASO. Gervais (1998) ethnographic analysis has become a foundation to assist in the evaluation framework for Project Sustain. During this year, we have seen the original ethnographic theoretical tool, which came out of the lived experience of ASO bereaved staff and volunteers, evolve into a broader assessment tool that can be applied to all ASOs.

From April 2000 to March 2001, Year Two, we saw the continued activities of building on organizational and community resiliency in Halifax and Vancouver. These two organizations have been broadening their understanding and internal resource development in managing the impact of HIV-related loss. Social action and community development is noted as an important aspect of this resilient skill building. We see this being demonstrated through these ASOs providing community involvement and leadership outside their ASO to help address the impact of HIV-related loss within community peers and peer agencies. The Winnipeg region continues to cope with the primary theme of organizational transition, due to its involvement with Project Sustain at a time of pivotal organizational change. The Nine Circles organization in Winnipeg is using Project Sustain to assist in organizational survival and massive organizational transition.

Also, during this past year, April 2000 to March 2001, we have also seen the evolution of organizational assessment tools and questionnaires which can assist future ASOs in identifying and finding solutions to the current and ongoing HIV-related loss challenges facing them. The facilitators had been challenged to apply Gervais' (1998) one-dimensional visual ethnographic analysis to assist ASOs in understanding the multi-layered impact of HIV-related loss. I have taken the ethnographic analysis and converted it into a three-dimensional cone to portray the dynamic interconnectedness and complex layering HIV-related loss has on our individual, organizational, and community functioning within an ASO. This work has now evolved into a second 'Grief Cone' (page 30) with attached assessment questions that can be used to provide individual, board and organizations a means to provide education and ongoing assessment.

(c) Year One Evaluation Report Excerpts

Participants have identified, through survey responses and group interventions, the ways they desired this national pilot project to assist with developing resiliency to the themes of grief and loss. Participants loosely defined the areas of assistance as follows: education regarding grief and organizational transition to staff and board,

individual and group intervention to assist with identification and beginning healing of loss issues, and strategy and local resource identification and development. Participants particularly found benefits from understanding loss and organizational theory and in the emotional expression and integration of unresolved personal/organizational losses. Participants identify a sense of hope that the project facilitators and/or local regional initiatives can assist in addressing unhealthy patterns and healing unresolved grief issues within organizations. The ethnographic data reveals that participants find unknown discovers regarding representatives within their own communities during group project activities. Project group activities appear to have begun to break down organizational group barriers. This is possible through the opportunities of self-discovery and sharing that are an essential part of this project.

Eight recommendations evolved out of the Year One activities, as follows:

1) ASO grief strategies need to be organizationally, community and culturally specific;
2) Organizational initiatives need to be co-ordinated to address or reduce the impaired communication patterns within ASOs;
3) Organizational efforts require creating and maintaining a healthy understanding and climate for the sharing of grief;
4) Organizations need to encourage and support creativity and a healthy balanced commitment to the work;
5) Advocacy is needed to secure funding to address these issues by highlighting key organizational and grief challenges;
6) Future national collaboration and education or training will be beneficial to ASOs to understand the impact of loss/grief and organizational change;
7) Future development of a organizational grief resource manual will be beneficial to ASOs; and
8) Future research using ethnographic and collaborative quantitative and qualitative approaches within ASOs will provide rewarding information.

Unique Background of Research Design

The assessment, interventions, and evaluation were a combined process for this national pilot project. This unique project has brought together several key leaders in the area of AIDS grief and multiple loss from distant locations in Canada. Yvette Perreault, Derek Scott and Val Gervais have combined their considerable experience, knowledge and collective skills with AIDS grief, multiple loss, and organizational transition within AIDS Service Organizations (ASOs). The Advisory Board of the AIDS Bereavement Project of Ontario has also assisted with their leadership and support to help create this national project by taking on additional Task Force roles along with pilot site representatives from Vancouver, Winnipeg and Halifax. Most importantly, the initiative and commitment within the leadership and staff of the three ASO regional partner agencies from Vancouver, Winnipeg, and Halifax made this project possible. Consequently, these collective skills and expertise have formed to create an efficient and resourceful project that would be extremely difficult to duplicate.

This research attempts to conceptualize the experiences and challenges of three ASO communities coping with the grief and multiple loss created by HIV disease. It also attempts to identify and initiate resilient coping strategies within these three diverse cultural communities that have evolving organizational contexts. Ethnography, or the study of culture, is a form of qualitative research that was used for this project evaluation. This approach attempts to provide us some guidance in understanding the experiences within these diverse organizational communities. This project process, like the study of culture, evolved over the course of the initially brief 15-month timeline. consequently, collaborative (Marshall & Rossman, 1995) and ethnographic (Agar & Hobbs, 1982; Ayers, 1989; Gervais, 1998; Swartzman, 1993) approaches to research were used for this national project. In particular Gervais' (1998) ethnographic analysis based upon her Canadian Master's Thesis AIDS Grief and Multiple Loss: The Experiences of Individuals Within an AIDS Service Organization, and modified ethnographic assessment model assisted in contributing to the assessment and analysis framework.

The study of culture or ethnography can take a considerable period of time, but by using knowledgeable insiders we effectively shortened the period it would take to meaningfully understand our experience under study. This project therefore combined the concept of auto-ethnography (Hayano, 1993) or insider research (Roseneil, 1993) by using three significant components. The first was ongoing collaboration with each pilot agency given their familiarity with their organizational culture and regional context. The second was knowledgeable facilitators in the persons of Yvette Perreault and Derek Scott. These two individuals are familiar with the lived experience of AIDS grief and multiple loss and ASOs. They have worked for six and three years, respectively, with the AIDS Bereavement Project of Ontario. They are also skilled in organizational and community development, and in assisting individuals and organizations in discovering healing within themselves and their communities. The third component was the need for the evaluator to function also as an insider researcher in the person of Val Gervais.

Strengths and Limitations

The major strength of this project is its collaborative nature. Through various mechanisms, from internal committees to staff surveys, each of the three communities actively participated in the development, design and implementation of the project. Through the Project Sustain Task Force members and participants in the regional mentoring component of the project, various individuals shared the roles and responsibilities in gathering, writing, and analyzing data. The integration of these various perspectives assisted in the validity of this study. While limitations on this process exist, the mid-year Task Force consultation and evaluation review identified key points and overall, affirmed the evaluation strength of this study. However, the limited time and finances for this national project made it impossible to create collaboration directly between or across the three ASO regional participants. Collaboration was achieved to varying degrees between Project Sustain staff and Task Force members, within each ASO and their regional community, and through an evaluation overview. Increased information validation by ASO staff and greater contact with other ASOs was a primary need identified by ASO participants.

A limitation is that the quantitative data is comprised of a small number of survey respondents who participated to varying degrees and uniquely within each region in Project Sustain activities. The intermittent nature of Project Sustain staff activity in the life of the organization and the significant organizational transitions and demands at the time of the project presented challenges in maintaining the continuity and momentum for participation in the gathering, completion, and receiving of evaluation information. Ongoing prompting by Project Sustain staff and Task Force members was required and achieved varying degrees of success. Ethnographic data is also summarized or interpreted through the biases and perceptions of project staff. However, ongoing clinical supervision for project staff, the external role of the evaluator, and consultations with Task Force members attempted to balance out any biases that may exist. Additionally, ASO Task Force members (Executive Directors for each region) and regional resource persons (where they existed) were invited to provide a written summary of their experience.

Data Collection and Analysis

The data for this national project was both formal and informal. The formal data included questionnaire survey results, the summaries of group interventions or ethnographic case notes from project staff, and a final evaluation questionnaire. The informal data included the feedback from Task Force meetings, a review of documents generated by a pilot site, and pre-visit assessment questionnaires generated in response to the project, the group dynamic experiences of the project staff Yvette Perreault and Derek Scott, and the researcher knowledge of Val Gervais. Unanticipated telephone conferences were also required between the facilitators and evaluator to review the formal and informal data that was evolving from pilot site activities, and to guide future regional involvement.

The formal data for this project was in three parts: assessment survey results, activity summaries of site visits or ethnographic case notes from the project staff, and final questionnaire evaluation. Given the short nature of the project the development of a new questionnaire tool was unlikely. A modified questionnaire, Appendix C, was therefore designed based upon the AIDS Bereavement Project of Ontario Evaluation of Support Worker Training (1998) and Gervais' (1998) ethnographic analysis. The questionnaire solicited personal and organizational data, coping strategies both individually and organizationally, and identification of the new challenges facing organizations.

A combined quantitative and qualitative analysis was therefore used to analyze the formal data. Questionnaire surveys required detailed analysis both quantifying information and providing detailed thematic analysis of responses to survey questions. These results were summarized in comparative tables. Data was grouped in categories to attempt to maintain the confidentiality of participants. Themes were identified within the responses of participants and grouped accordingly.

IV. Resiliency Map Initiative

(a) Description and Development

The Resiliency Map is a 16-square foot floor blanket or quilt with concentric circles depicting self (centre), emotional reactions/ relation to others (next circle), community/social networks (third circle), and the socio-political environments (outside circle). These concentric circles are intersected by two meridians: one representing motivation and commitment, and the other representing shared personal and organizational values. Originally conceived of as a flat one-dimensional cone image, the Resiliency Map has evolved into a multi-dimensional tool. It can be used for assessment, problem-solving, program planning, team-building, psychological, emotional and spiritual healing, evaluation and other purposes requiring a purposeful identification of stressors, current coping strategies, new coping strategies, and required coping strategies.

The Resiliency Map allows people to weave a narrative as they literally walk on this floor map and articulate their journey with or in response to HIV. The Map creates an opportunity for people to describe their motivation and attachment for AIDS involvement, the stressors and coping strategies of self, the stressors in AIDS-related interpersonal relationships balanced by their strategies of resiliency. The Map provides a rich opportunity for individuals to both identify the impact of stressors and share observations about the organizational, community and larger socio-political responses. Through this process of identifying current stressors and resiliency strategies, new individual and collective strategies emerge based on shared purpose, motivation, and commitment.

While the Resiliency Map has been conceptualized, created and used within the context of existing workers in community-based AIDS service organizations, it is a new resource and as such it has not been documented, nor is it currently widely used. It has been piloted with many types of human service workers, including an aboriginal women's shelter, palliative care nurses and ALS care providers.

This model provides a means to help situate the individual and collective experience of loss and hope/stress and coping within individual, relational, organizational, and socio-political contexts. The model recognizes that people have considerable of motivation and commitment in response to HIV, shared personal and organizational values, and individuals and groups are able to assess, identify, and create resiliency.

From nine years of work, APBO has identified resiliency as a core competency in AIDS work. **Resiliency is the capacity of individuals and groups to move forward with hope, clarity and effectiveness in the face of the multiple loss, complex grief, and ongoing transition related to HIV/AIDS.** It is our belief that grief and loss are pervasive characteristics of HIV/AIDS that limit people's capacity to effectively integrate prevention knowledge into their behavioural patterns. Trauma literature and direct experience would also have us believe that they have a significant impact on people's ability to effectively access or provide care, treatment and support. Rising

numbers in urban infection rates suggest that the information of AIDS education is not enough to support people to make healthy choices. The Resiliency Map is a vehicle to engage in a meaningful dialogue on the complex issues that HIV/AIDS raises in our communities - grief, loss, hope, resiliency, capacity, death, sexuality, entitlement, empowerment, rage, community - but which we have not yet found sufficiently complex theory and shared language to explore.

The Resiliency Map is derived through the experience of the AIDS Bereavement Project of Ontario's Project Sustain, a 3-year national project designed to "identify the impact of AIDS grief and multiple loss, provide regional comparison of the unique challenges facing ASOs, and attempt to identify and help initiate resilient strategies within three distinct regional AIDS Service Organizations in Vancouver, Winnipeg and the Atlantic."[1]

Through the experience of Project Sustain, and based upon previous research[2] a visual theoretical framework (see 'Cone', page 4) was developed to "depict the interconnectedness of our losses and the ways they are complexly layered in the day to day lives of ASO workers".[3] This 'Cone' provides a means for ASOs to identify the impact, recognize our coping strategies, and develop new forms of resiliency in response to HIV-related grief.[4] While the 'Cone' was an excellent conceptual tool, its developer, Val Gervais, perceived it may have different utility as a vehicle for experiential self-learning and facilitating community dialogue if it were actually transferred to a physical assessment tool. National training participant feedback expressed a need to explore further how "practical tools and techniques using this model be developed, tested and disseminated". By February 2002 a first rendering of a floor size Resiliency Map was created. It was first used in March 2002 with the Ontario AIDS Network PHA Caucus.

This photo of the Map was taken in April, 2002, at the Project SUSTAIN National Facilitator's Training:

[1] Perreault, Yvette and Gervais, Valerie. Project Sustain: Creating and Reinforcing Supports for ASO Workers Coping with the Impact of Multiple Losses, Year One Evaluation Report, February 1999 to March 2000

[2] Gervais, Valerie J. AIDS Grief and Multiple Loss: The Experiences of Individuals within an AIDS Service Organization, unpublished Masters thesis, University of British Columbia, 1998

[3] Perreault, Yvette. Sustaining Healthy AIDS Service Organizations: A Workbook on Grief, Multiple Loss & Transformation, Draft, 2002).

[4] Ibid

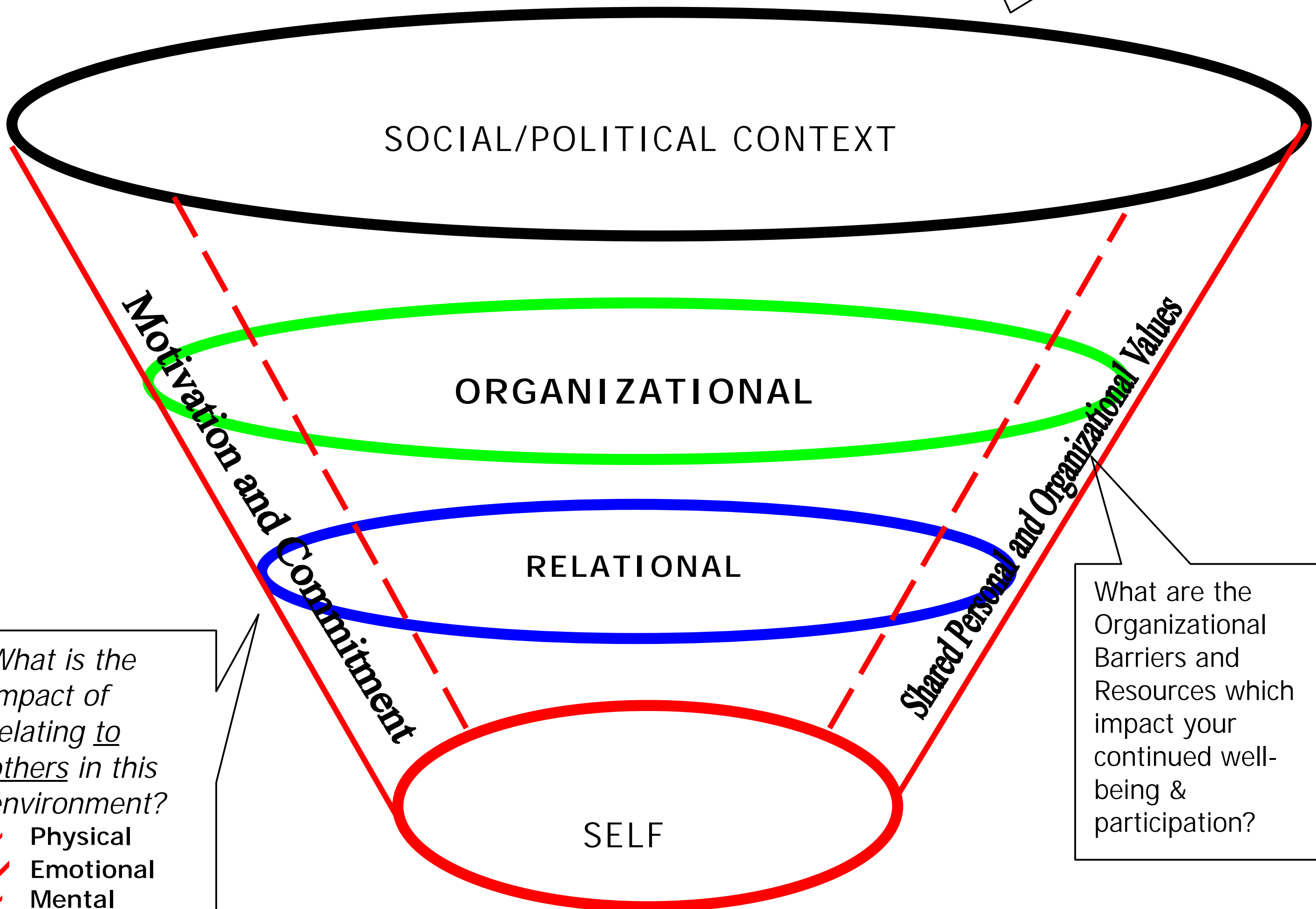
The Resiliency Map is based on:

- the Ethnographic Tool and the 'Cone' developed by Gervais[5] ,
- three years of a research generated through Project Sustain,
- and the experience of the AIDS Bereavement Project of Ontario working with people living with and impacted by HIV/AIDS in Ontario.

[5] Gervais, Valerie J. AIDS Grief and Multiple Loss: The Experiences of Individuals within an AIDS Service Organization, unpublished Masters thesis, University of British Columbia, 1998

'The Cone'

What are the Barriers and Resources in the community and larger social/political context?



What is the impact of relating to others in this environment?

- **Physical**
- **Emotional**
- **Mental**
- **Spiritual**

What are the Organizational Barriers and Resources which impact your continued well-being & participation?

What initially, and now, continues to motivate you to be in this work?

Sustaining Balance between Loss and Hope:
Layers of Stressors and Coping Strategies

V. Final Project Implementation Issues

(a) National Training Priorities and Questions

Project SUSTAIN was faced with a significant challenge to respond to the outcomes of the September national training of Regional Resource People. We hosted a second national training for Regional Resource People in Toronto, in spring, 2002. Eight additional participants from Ontario contributed to the training and to the evaluation of materials. At this training, we focussed on the priority issues of:

- Further work and tools training with the 'Grief Cone' theoretical tool and Resiliency Map.
- Further training on holistic intervention techniques.
- Specific planning on supporting the trained Regional Resource People in the coming months.
- Discussion on supporting work within the Aboriginal community.

The five major questions that arose were:

1. How to fulfill the national mandate of Project SUSTAIN mentoring work:
   (i) for Resource People working within an Aboriginal context,
   (ii) to support new work specific to that constituency
   (iii) to share those skills with the broader pool of Resource People, who also need to be responsive to Aboriginal cultural frameworks?

2. How to support the response from the trainee's evaluations asking for more specific skills training on holistic intervention techniques?

3. What can be done to support the trained Regional Resource People?

4. How will the SUSTAIN Training Manual become a usable resource for ASOs in Canada, particularly for the remaining Atlantic provinces, Alberta, Saskatchewan and the northern territories that Project SUSTAIN has not worked with. What about Quebec?

5. The "Grief Cone" theoretical tool, developed through Project SUSTAIN, presents a complex model for multi-layered organizational interventions, and was very successfully utilized in the national facilitator's training. However, given that feedback from participants indicates that this training provided only an introduction to this new theory and practise, how can practical tools and techniques using this model be developed, tested and disseminated?

(b) Regional Resource Person Development

We can now reflect and evaluate the efficacy of our original projections for the Years II and III workplan. We have made several changes based on the inherent commitment of the SUSTAIN strategy to supporting workers in the context in which they live. This value resulted in the selection of Resource People being carried out by each individual pilot agency, based on their criteria, or in consultation with other Resource People in the region to determine a best fit. In this way, we might characterize the intimate nature of the Resource Person as a unique relationship for each agency. At a national level, we provided a general framework of skills and relationship to a facilitator, the Regional Resource Person Job Description (see Appendix IV). At a local level, the selection of a Resource Person prompted focused discussions amongst staff to evaluate what type of support would assist them. It also served to bring tensions closer to the surface, in order to look at what type of an approach would help to clear them within the agency.

By agreeing to participate as pilot sites, agencies opened to the possibility of external support for the various challenges faced by both the individual staff and agencies as a whole. Discussions at staff meetings and even staff surveys as needs assessments for upcoming events, i.e. Village Clinic, functioned as a starting point for the work of naming issues and identifying challenges, which could then be addressed more overtly with the facilitated sessions.

The crucial ingredient to the success of this project has been the willingness of Regional Resource People to adapt the process as it was originally outlined and invest their personal time to establish a strong consultative role with the agencies. The original workplan and budget only accounted for their time spent delivering workshops. For future work, the assessment and on-going consultation responsibilities of Resource People need to be both planned and budgeted. In some cases, where there was a short lead time from an agency expressing interest in being a pilot and the first intervention, a Resource Person in BC conducted full staff interviews in order to bridge people into the work and establish necessary trust levels.

Regional Resource People reported that the various assessment tools provided a useful discussion framework. The tools validated all the range of impacts of grief, loss and transition and gave language to help people name and normalize various responses and priorize how to address them as a group. While the assessment questionnaires provided a strong conceptual framework, they opened up tough emotional questions on loss in a very cognitive format. Because of this limitation, there was feedback from both East and West Regions, that it was the time that Resource People spent in direct consultation with staff and managers which proved essential in the design of interventions that had maximum benefit to the staff.

(c) Facilitator's Training Manual

The component has provided the biggest challenge to implementation has been the Training Manual. Specifically, the structuring of early writing and research phases (Phase I-III) prior to the national training proved to be a mistake in the developmental process. Our primary learning from Year I clearly demonstrated that the ABPO model was not directly translatable into other regions, and that room had to be left in the piloting process for the 'seed' of Project SUSTAIN work to take root in each distinct environment. The fundamental lesson from our national mentoring process has been that the first harvest of these different regional trees has brought new and distinct ingredients into the creation of a training manual. We can now conclude that because of the realities of AIDS organizations that the most effective research is through direct interventions.

We can now see that in order to support Resource People, the frameworks themselves have needed to be tested and re-developed, not just a fine-tuning of various intervention tools. We had originally designed the testing process with our Phase IV of 'Refinement' on this false premise of minor modifications to existing tools. Strong collaborative relationships were established at the September Training with Resource People, Facilitators and the Evaluator sharing new ideas, working in the field, de-briefing and envisioning new applications of various tools and exercises. As the dialogue continued, the 'Cone' emerged as a central conceptual framework and as a way to organize the spectrum of intervention tools. It also was given an application as an assessment tool.

The outcome of this process has been beyond our original scope, whereby the new theoretical model, 'the original Grief cone' from Year II, has also become a new direct intervention tool for use with group exercises by Regional Resource People. As introduced in section VI. Resiliency Map Initiative. This element, a late-breaking fourth quarter development, is a pivotal success of the project and was a primary focus of our second Facilitator's training. Unanimously, Resource People in all regions, working with diverse constituencies, will be utilizing the tool to anchor ASO participants in their lived experience of resiliency.

Another element in the emerging national picture of sustaining ASOs, which came from the de-briefing and on-going discussions of Resource People, relates to a common theme of ASO transition and change. The two main components of this pressure come from de-stabilization, or on-going uncertainty, of provincial funding for Atlantic and British Columbia regions; and secondly, from the high level of staff turnover and significant gaps in the skill levels, connection to clients, etc. in staff groupings between 'long-term' workers and those who are new to the work. Therefore, these realities necessitate that the Resource People develop a flexibility and responsiveness to the constantly changing context of AIDS work. This is not consistent with our original training model that was predicated on the skills base for the work having a more static character.

In the last year in Ontario, the AIDS Bereavement Project has undertaken a regional ACAP grant, called "Survive and Thrive" to work with the resiliency of long-term PHAs and the effects of multiple loss. This project was developed in response to an emerging issue and is creating a new series of intervention tools that we would like to share with the national Resource Person team.

List of APPENDICES

Appendix I — Assessing the Impact and Themes of Loss

Appendix II — Organizational Assessment Questionnaire

Appendix III — Year One Research Data

Appendix IV — Regional Resource Person Job Description

AIDS Bereavement Project of Ontario

Assessing the Impact and Themes of Loss

An important stage in addressing loss is reflection and assessment of the impact of losses and transitions. This information is absolutely confidential - however, you can let us know who you are if you choose.

1. Some Information about you:

age__________ gender_______

Anything else you'd like us to know about you?

____

2. About Your AIDS Work:

a) Present job title____
b) Length of time as a paid worker________________________
c) Length of time as a volunteer worker (if applicable)_____________

About your Experience with DEATH & GRIEF:

3. Professional:

a) How many of your agency's clients that you have known have died?
(estimate if necessary)
______0 ______1-3 ______4-6 ______7-10 ______10-20+
______20-50 ______50-100 ______100+ ______300+ ______500+
____________specific number

Personal:

b i) Number of losses due to death, not necessarily AIDS-related.

______Colleagues/co-workers ______Spouse/Partner
______Friends ______Aunts/uncles/cousins

______Acquaintances
______Parents
______Child/ren
______Grandparents
______Siblings
______Pets

b ii) Please describe any significant transitions that have occurred in your life over the last two years (moving, new job, illness, partner break-up etc.).

____
____
____
____

b iii) Did you experience any physical effects which may have been due to your grief and/or transition losses? If so, please describe.

____
____
____
____

b iv) Did you experience any emotional and/or psychological effects that you think were due to your grief and/or transition losses? If so, please describe.

____
____
____
____

b v) Please comment on the effect of grief and/or transition losses (if any) on your social and/or sexual life.

____
____
____

b vi) Has your experience of grief and/or transition losses had any effect on your spirituality or belief system? If so, please describe.

____
____
____
____

b vii) Do you now, or have you in the past, sought support or assistance with your grief and/or transition losses? If so, please describe.

____
____
____
____

We are interested in some of the Unique Characteristics of you and your agency, which the next few questions address.

4. Core Connection:

a) Please describe your first connection to AIDS.

____
____
____
____
____

5. Emotions:

a) Please comment on the specific emotional demands of AIDS work.

____
____
____
____
____
____

b) What emotional reactions have you noticed in the workplace?

____
____
____
____
____

____

6. **Common Themes:** The following questions will help us to explore common themes among workers which are related to significant loss and/or transition experiences.

1. My grieving feels like its been going on for a very long time and/or is excessively intense.

YES **NO** if yes, please say more____
____
______

2. There are times when my grief is just not there.

YES **NO** if yes, please say more____
____
______

3. My grief sometimes shows as getting really mad or edgy, more than I am comfortable with.

YES **NO** if yes, please say more____
____
______

4. As part of my grieving, I sometimes withdraw completely from my social life.

YES **NO** if yes, please say more____
____
______

5. Sometimes all my losses just don't seem real.

YES **NO** if yes, please say more____
____
______

6. Sometimes I think of all my losses and it's not a big deal, I just go on.

YES **NO** if yes, please say more____
____
______

7. It sometimes seems that all the losses are for nothing – there's no sense.

YES **NO** if yes, please say more____
____
______

8. I sometimes feel like I am watching my life from a distance.

YES **NO** if yes, please say more____
____
______

9. I sometimes feel guilty for still being alive.
YES **NO** if yes, please say more____
____
______

10. I don't make new friends or connections any more.
YES **NO** if yes, please say more____
____

7. Coping

a) The demands of AIDS work lead us to develop and expand self-care strategies. Please describe your ways of taking care of yourself.

____

____

____

____

b) What have you noticed in your staff, in terms of how they take care of themselves?

____

____

____

____

AIDS Bereavement Project of Ontario

ORGANIZATIONAL ASSESSMENT QUESTIONNAIRE

The Basics

1. Name of the organization: ____________________________________

2. Position of person completing this questionnaire:__________________

3. Length of time with the organization: paid________unpaid______

4. In general terms, what is the mission of your group?

5. What programs and services does your organization offer? Is your service delivery area local or provincial?

6. How many staff does your agency have?

7. How many volunteers?

8. How many Board members?

The Context

9. In your opinion, what are the most important challenges facing your agency right now?

10. Can you identify significant transitions you agency has faced in the recent past?

11. What are the key strengths that your agency has now?

Organizational Impact of Loss

12. In your experience, what have been some of the impacts, if any, on your organization of:
    a) grief and multiple loss?

    b) change and transition?

13. In terms of your agency, how have these impacts shown themselves positively?

14. In terms of your agency, how have these impacts shown themselves negatively?

Acknowledging and Integrating Loss

15. Please comment on your agency's policies, procedures and/or practises in the following areas related to grief and loss:

- Training on grief and loss integrated into orientation of:
  a) staff

  b) volunteers
- Policy on bereavement or compassionate leave for:
  a) staff

  b) volunteers

- Formal mechanisms to acknowledge loss due to death

- Formal mechanisms to acknowledge transitions: such as closures for volunteers/staff

- Staff development sessions to examine and address the impact of loss on workers (such as Care for the Caregiver retreats)

- Please describe any additional methods your agency has in place for responding to loss.

Organizational Culture

16. From your experience, please comment on your agency's current style of working with grief and loss issues: (if there are several responses, please indicate the circumstances in which these are likely to take place)

    - Formal presentations on the topic looking at theoretical aspects and relevance to the work; development of policies and procedures if required

    - Round table discussions or group sessions where workers can openly share the emotional impact of grief and loss

    - No formal structure, people tend to gather informally and talk through issues with colleagues they feel personally comfortable with

- Structured facilitated rituals and memorializing
- Nothing happens
- Other

17. Has your agency previously held workshops or presentations on grief and loss?
____Yes ______No

If yes,
a) What was useful about that experience?

b) What was not useful?

18. What do you see as grief or loss-related issues currently facing your organization?

19. What, if anything, would you like to see in place for your agency in order to enhance the response to these grief and loss-related challenges?

20. What do you expect would be different in your agency, and for your workers, as a result of the additions/changes indicated in #19?

Many thanks for taking the time to complete this survey!

Table 2 – Participant Profile from Survey Results

Respondents	VANCOUVER	WINNIPEG	ATLANTIC REGION
Age	26 – 46 years Average (34 years)	23-56 years Average (36 years)	31-58 years Average (41years)
Gender	F (5) M(4)	F (8) M(2)	F (6) M(2)
AIDS Work – (Paid) **(Unpaid)**	< 1 year – 6years Average 3 years <1 year (One participant did not separate out the work and collectively it was 16 years)	< 4 years Average 3 years 0 – 8 years Average (1.6 years)	< 1 year – 3 years Average (1.8 years) (0-10years) Average (3.7 years)
Professional Death & Grief Experiences	Range of deaths from 0 to 300+ Average 20-50 deaths	Range of deaths from 1 to 20+ Average 7-10 deaths	Range of deaths from 0 to 50-100 deaths Average 7-10 deaths

Job Title		
	Volunteer/Support Coordinator	**11**
	Executive Directors	**7**
	Education Program	**5**
	Administrative Support	**3**
	Physician	**1**
	N=27	

The analysis of Personal Losses Due To Death Not Necessarily AIDS (Table 3) revealed a large number of acquaintance deaths (238). Participants identified that the range of deaths were between four to many, and the average number of deaths for 16 of the 27 participants was >14.8 given at least six of the participants did not provide a specific number value. Participants described most frequently (22 of 27) and in large numbers (123) the loss of a friend with the average being 5.6 deaths per participant. Additionally, of note for a smaller number of participants (8 of 27) they had experienced a large number of deaths (36) of colleagues/coworker with the average being 4.5 deaths per participant. An analysis of the familial deaths reveals participants have most frequently lost a grandparent, then aunt/uncle/ cousin, and finally a parent. The loss of siblings, spouse, and children are least likely to occur. Over half of the participants identified the loss of a pet as significant to them.

In summary, we see that the Atlantic Region represents the most mature, in relation to age and unpaid experience with AIDS work. Atlantic survey respondents were more likely to experience the personal loss of a friend and parent. The youngest survey participants live in Vancouver and they often have the least combined paid and unpaid experience with AIDS work and have the second largest acquaintance loss experiences. In contrast, the ethnographic data suggests that the Winnipeg region may represent the greater experience with HIV/AIDS from “2 to 20 years with a median of 10 years”[1]. “Project staff also commented on the extraordinary length of time (Winnipeg) workers had been connected to HIV/AIDS, in contrast to workers in other parts of the country”[2]. Additionally, if you live in the Winnipeg region you are the most likely to experience the greatest number of personal losses due to a death of a colleague or coworker. Winnipeg respondents also have the largest number of acquaintance loss experiences, whereby it is slightly larger than Vancouver participants.

[1] Ethnographic data from page 3 of summary of Intervention #5 in Winnipeg June 11-14/99.

[2] Ethnographic data from page 3 of summary of intervention#5 in Winnipeg June 11-14/99.

Table 3 – Personal Losses due to death, not necessarily AIDS				
Type of Relationship	**Range of Deaths Experienced**	**Average Number of Deaths Experienced**	**Total Number of Deaths Experienced**	**Number of participants who Identified having experienced this type of loss**
Colleagues/co-workers	2-13	4.5	36	8 of 27
Friends	1-way too many	5.6	123	22 of 27
Acquaintances	4- many (Several participants did not provide a number)	14.8	238	16 of 27
Parents	1-2	1	15	16 of 27
Children			2 (1 child / 1 miscarriage identified)	2 of 27
Spouse/Partner			2	2 of 27
Aunts/uncles/cousins	1-all	4	85+	20 of 27
Grandparents	1-4	2.3	57	24 of 27
Siblings	1-3	1.2	6	5 of 27
Pets	1-10+	3.6	54	15 of 27

Table 4 – Positive Impact Of Grief
Comparison Of Grief In Three Organizational Contexts

VANCOUVER REGION

- ***Commitment to the work***
  - Commitment to the work **(V2)**
- ***Creation of a supportive work environment to respond to grief***
  - Acknowledgment of the need for self care **(V1)**
  - Helps us be close-knit because of being survivors. **(V5)**
  - High levels of mutual support **(V1)**
  - With intervention of ABPO, staff can be brought together over emotions but the challenge is to maintain it through coping with organizational change **(V8)**

Unknown (V9)

- **No comment (V7) (V6) (V4) (V3)**

MANITOBA REGION

- ***Commitment to the work***
  - Commitment to get the work done **(W2)(W6)**
  - Commitment to the work and clients **(W3)**
  - Passionate personal and professional commitment **(W6)**
  - Skills of staff and organization are very effective **(W10)**
  - Endurance**(W9)**
  - People continue to hard work for low wages and with diminishing resources **(W5)**
  - Long term staff **(W7)**
- ***Creation of a supportive work environment to respond to grief***
  - Develop new strategies for training/connection and mutual support with volunteers **(W1)**
  - Dynamic individuals (staff and clients) who can respond to any situation instantaneously (**W10)**
  - Continued sense of passion and creativity **(W7)**
  - Creation of environment where we have fun together in work and play **(W6)**
- **No comment (W8)(W4)**

ATLANTIC REGION

- ***Commitment to the work***
  - People are committed and dedicated **(AED2)**
- ***Creation of a supportive work environment to respond to grief***
  - Motivated to learn about grief **(AED5)**
  - Creates social emotional intimacy **(AED5)**
  - Creates a social environment where people feel comfortable to grieve **(AED2)**
  - Self care strategies are begun **(AED3)**
  - Higher levels of awareness of support needs for staff and PHA's **(AED1)**
- **Blank (H1)**
- **Uncertain (H2), (H3)**

Table 5 – Negative Impact Of Grief
Comparison of Grief in
Three Organization Contexts

VANCOUVER REGION

Burnout (V4)

- Staff Turnover **(V5) (V1) (V8)**
- Lost expertise due to constant staff changes **(V1)**
- Extended Leaves **(V5) (V1) (V8**
- Heart Fatigue **(V8)**
- Increased symptoms in Management Team **(V8)**

Significantly Impaired Care and Communication

- Organizational mood poor and Increased pre-occupation with non-things **(V8)**
- People working in isolation **(V9)**
- Mistrust **(V2)**
- Dysfunction**(V2)**
- Division between staff because of the workload volume (W8)

MANITOBA REGION

Overworking (W6)(W2)

- Staff/ volunteers/ board members moving to other ASO's – never leaving AIDS work **(W7)**
- Staff working unpaid overtime **(W5)**

Impaired Care and Communication

- Communication is unclear, people are sometimes edgy, agitated, and frustrated
- People creating and maintaining chaos in order to survive (W7)
- Not enough or we don't make time to stop and grieve **(W6) (W2)**
- Shot-gun anger **(W3)**
- Denial of Impact of Grief **(W7)**
- Stress **(W7)**
- Mistrust **(W7)**
- Suspicion of new people and ideas **(W3)**

ATLANTIC REGION

Staff/Volunteer/Board Burnout/Turnover

- Staff, Volunteer, Board Burnout
- Turnover

(AED5) (AED4) (AED3) (AED1) (AED2)

Impaired Care and Communication

- No time to listen to each other **(AED1)**
- Misdirected Anger **(AED5)**
- Staff Sick Days **(AED3)**
- Drinking and Using **(AED3)**
- Poor Time Management **(AED1)**
- Stress **(AED1)**
- Sharper and shorter with each other/ and some retreat into a shell **(H3)**

- Hard to bring agency together as a group (V1)
- People screw up their communication styles (V2)
- Denial of grief and no formal recognition process (V9)
- Schism between front-line workers (downstairs) and non-front-line workers (upstairs) **(V5) (V1)**
- Workers lashing out at any and all vulnerable or safe targets **(V4)**
- Staff skilled at looking after others issues and losing sight of personal care and repair and therefore desires to be cared for by agency **(V8)**

Animosity/ Lost faith in management

- Poor Executive Management **(V4)**
- Lack of faith in Executive Management ability and credibility **(V4)**
- Fragmented **(V4)**
- Lack of focus or direction **(V4)**
- Top down change in continuous cycles **(V8)**

No Comment (V6) V3, V7

Loss Of Committed Individuals

- No one shows up for organization events **(W2)**
- Staff Turnover **(W7)**
- Uncertain or inactive volunteer commitment – because of uncertain role in new face of AIDS work **(W1)**

Reduced Organizational & Interagency Functioning

- Major destructive behavior towards the organization and its functioning **(W5)**
- Political sabotage **(W3)**
- Coup d'λ tat **(W3)**
- Hostility sometimes between or with organizations, general community, and workers (W6)
- Law suits (W3)
- Amalgamation of three organizations which historically have not liked each other **(W1)**
- Uncertain program planning – given Palliative Care Teams not needed at this time **(W1)**

No Comment (W4)

Denial/Unawareness of Impact of Grief

- Grief is not dealt with/ no support for Staff **(AED4) (AED1)**
- New Staff and Board have little personal knowledge or experience with grief **(AED5)**
- Board not listening or unaware **(AED1)**

Negative Impact on Client Support

- Lost focus on financial aspect of running an office instead of client needs **(AED5)**
- Conflict between Straight and Gay Clients **(AED5)**

Blank (H1)

Physical Effects Due to Grief

Participants identified a variety of physical effects due to grief as outlined in Table 6. Twenty of the twenty-seven survey respondents described awareness of physical effects; the **most frequently noted being fatigue,** when we combine the results of comments in Table 6 and Table 7 where twelve of 20 respondents identify with this physical effect. Sleep disturbance and pain was identified by nine of 20 participants. Headaches were identified as the most frequent form of pain. Six of 20 participants then noted grief having an impact on their level of overall health and susceptibility or exacerbation of illness, and changes in appetite. Decreased mental concentration was noted next in five of 20 participants when Table 6 and 7 are combined. Anxiety, nausea, moodiness, depression, tearfulness and light sensitivity were also noted. Comparatively between regions, we find an important observation that participants in the Atlantic Region denied any awareness of physical symptoms with five of the eight survey respondents unable to identify any physical effects of grief. This may identify a need around educational intervention in this particular region especially given they represent areas of leadership within their organizations.

Table 6 – Physical effects of grief
(20 of 25 participants identify physical effects of grief)

Type of symptom	*Number of participants who identified this effect*
Fatigue	**9 of 20 participants**
Sleep Disturbance (Insomnia/ Nightmares)	**9 of 20 participants**
Pain Headaches/ Back or Neck/ Joint Pain	**9 of 20 recognize physical pain** 5/ 3/ 1
Susceptibility to Illness or exacerbate chronic illness	**6 of 20 participants**
Changes in Appetite Loss of Appetite / Eating More	**6 of 20 participants** 5 / 1
Decreased Mental Concentration	**4 of 20 participants**
Nausea	**3 of 20 participants**
Anxiety – Anxiety Attacks/ Chest Pain	**2 of 20 participants**
Moodiness	**1 of 20 participants**
Tearfulness	**1 of 20 participants**
Depression	**1 of 20 participants**
Light Sensitivity	**1 of 20 participants**

Emotional or Psychological Effects of Grief

Participants more frequently identified with having emotional or psychological effects of grief (Table 7) rather than physical effects. The most frequently identified was sadness and depression. One participant identified depression as a physical effect of grief from Table 6. In total, we find eleven of 23 survey respondents therefore identify **sadness or depression as the most frequently recognized emotional or psychological effect of grief**. Numbness, anxiety, and social withdrawal/isolation/loneliness are next most frequently identified in six of 23 participants. Anxiety being noted as an emotional effect in six of 23 participants when you combine Table 6 and Table 7. Participants then identified most frequently anger in five of 23 participants. Crying or tearfulness is recognized in five of 23 participants when you combine the results of both tables. Three of 23 participants identify moodiness or sudden mood changes because of grief when you combine the results of the two tables. They also identified denial/repression, tension, distrusting, displacement, difficulty concentrating, guilt, and reduced productivity.

Table 7 – Emotional or Psychological Effects of Grief (23 of 25 identify this experience)

Type of Symptom	***Number of Participants who identified this effect***
Sadness and Depression	**10 of 23**
Numbness/Detachment	**6 of 23**
Social Withdrawal/ Isolation/ Loneliness	**6 of 23**
Anger	**5 of 23**
Anxiety /Nervousness /Fear	**5 of 23**
Emotional and Physical Fatigue	**3 of 23**
Hopelessness	**2 of 23**
Crying	**4 of 23**
Sudden Mood Changes	**2 of 23**
Denial/Repression	**2 of 23**
Tension	**1 of 23**
Distrusting	**1 of 23**
Displacement	**1 of 23**
Difficulty Concentrating	**1 of 23**
Guilt	**1 of 23**
Reduced Productivity	**1 of 23**

Table 8 – Emotional Demands Of AIDS Work
Comparison Of AIDS Work In Three Organizational Contexts

VANCOUVER REGION	MANITOBA REGION	ATLANTIC REGION
♦ ***Coping with the Grief around death and loss*** ➢ Feelings of Sadness **(V4) (V9)** ➢ Challenge to be up or perky around lots of deaths **(V2)** ➢ Impotence against agonizing death**(V8)** ➢ Flooding of feelings**(V8)** ➢ Anger/ Irritability **(V8)** ➢ Avoidance **(V8)** ➢ Humor to relieve the impact of the work **(V5)** ➢ Guilt**(V8)** ➢ Joy **(V8)** ➢ Fulfillment and Accomplishment **(V8)** ➢ Celebration **(V8)** ➢ Ritual and Magic**(V8)** ➢ Transitioning **(V8)** ➢ Inspiration **(V8**	♦ ***Challenge to Maintain Self Care*** ➢ Fatigue **(W6) (W8) (W3) (W10)** ➢ Maintaining Boundaries for Self-preservation **(W6)(W7)** ➢ Maintain professional – not allow my stuff to become clients' stuff **(W9)** ➢ Coping with the emotional responses in many sectors **(W3) –** sad and frustrated **(W10)** ➢ Never ending demands – doing too much, too little time, feeling of chaos and panic **(W7)** ➢ Continual need for flexibility **(W10)** ➢ Caring – compassion, sympathy, empathy, understanding, sensitivity with clients who may be angry, abusive, extremely needy, aggressive **(W5)** ♦ ***Coping with grief*** ➢ Continue to work without cleansing grief **(W2)** ➢ Coping with death and survival guilt **(W1)**	♦ ***Fatigue*** ➢ From the constant demands of 'being present' for isolated clients – those HIV+ and family, and staff **(AED5) (AED2)** ➢ Those not HIV+ have no support **(AED4)** ♦ ***Being away from family (lonely)* (AED3)** ♦ ***Coping with Emotions of grief*** ➢ Sadness **(AED3)** ➢ Relief that the suffering is over **(AED3)** ➢ Self awareness of the impact of multiple deaths **(AED1)** ➢ Inadequate time to grieve **(H3)** **Blank (H1), (H2)**

- ***Coping with the Complex and Crisis Nature of Client Needs***
  - Coping with broken, hurt abused people hurts the heart **(V9)**
  - Highly emotional work context **(V7)**
  - Learn to not overreact to anything **(V5))**
  - Truckloads of compassion (**V9, V4)**, patience and non-judgmental capacity **(V9)**
  - Constant Battle against fear and hopelessness
  - Coping with the Pandora's box of HIV Disease. Challenge to face the diverse issues of poverty, neglect, racism, sexism, marginalization, abuses of power, etc. **(V1)**
- ***Challenge to maintain Boundaries***
  - Strong sense of self and ability to keep one's personal issues separate from work and clients **(V4)**
  - The professional boundary guidelines do not take into account the nature and sized of the gay community **(V6)**

- **Blank(V3)**

- ***Loss of serving familiar Clientele***
- ***Uncertain future and funding and loss of organizational identity with amalgamation* (W1)**
- ***Lack of understanding outside AIDS community* (W8)**

Blank (W4)

Table 9 – Emotional Reactions In the Workplace
Comparison Of AIDS Work In Three Organizational Contexts

VANCOUVER REGION

- ***Anger*** (V2) (V4) ***/Frustration*** (V2) (V4) ***Resentment*** (V4, V8)
- ***Symptoms of Burnout***
  - Feeling cut off **(V6)**
  - Distance from other co workers **(V4)**
  - Clichés **(V1)**
  - Disillusionment **(V4)**
  - Resistance to change
  - Poor ability to cope **(V4)**
  - Lack of vision **(V4)**
  - Lack of interests in client's needs **(V4)**
  - Cynicism **(V1)**
  - Lack of Ability to Trust, try, extend the benefit of doubt **(V1)**
  - Stress Leaves **(V9)**
- ***Responses to Grief (V8)***
  - Impotence against agonizing death**(V8)**
  - Flooding of feelings**(V8)**
  - Anger and Irritability **(V8)**
  - Avoidance **(V8)**

MANITOBA REGION

- ***Diverse Emotional Responses***
  - Anger, & Frust*ration* **(W5) (W3)** Displacement of anger **(W10) (W7) (W8)**
  - Fear and Anxiety **(W8)(W5)**
  - Sadness **(W5)**
  - Burnout **(W5)**
  - Defensiveness **(W9)**
  - Walling off and working in isolation **(W9)**
  - Flooding **(W3)**
  - Detachment **(W3)**
  - Stress **(W7)**
  - Cliques & Gossip **(W7)**
- ***Overexertion of energy & Fatigued workers*** **(W10) (W7)**
  - Compulsiveness (W3)
- ***Emotional Responses to Grief***
  - Tears **(W2)**
  - Heartbreaks **(W2)**
  - Supporting Other Staff **(W2)**
  - Tired, emotionally exhausted and ill in response to a wave of deaths

ATLANTIC REGION

- ***Emotional Responses to Grief***
  - Anger/Short tempered **(AED5) (AED3) (AED1) (H3)**
  - Sadness **(AED5) (AED3) (H2)**
  - Withdrawal /isolation **(AED5) (AED1) (H3)**
  - Feeling disconnected **(AED1) (H3)**
  - Stress **(H2)**
  - Self centeredness (poor Me) **(AED1)**
- ***Coping Responses to Grief***
  - Humor **(AED5)**
  - Kindness **(AED5)**
  - Love **(AED5)**
  - Grief is minimized because of the inadequate time to cope with the constant demands **(AED2)**
  - **Blank (H1) (AED4)**
-

- Guilt**(V8)**
- Joy and Celebration **(V8)**
- Fulfillment and Accomplishment **(V8)**
- Ritual and Magic**(V8)**
- Transitioning **(V8)**
- Inspiration **(V8)**

- ***Coping with grief and loss***
  - Bonding around loss **(V7)**
  - Humor to relieve the impact of the work **(V5)**
  - Caring and Compassionate Coworkers **(V9)**
  - Friends are around me **(V9)**

- **Blank(V3)**

(**W6)**

- ***Responses to Organizational Transition***
  - Irritability **(W1)**
  - Suspicion regarding future amalgamation **(W1)**
  - Current power dynamics creating environment of smoldering anger/distrust which is sapping personal and collective energies **(W1)**
  - Anger/fear **(W1)**
  - Not enough time to express unspoken expectations **(W1)**

Blank (W4)

Effect of grief on Social/Sexual Life

Participants identify that grief also has a significant impact on their social and sexual life as summarized in Table 10. **Grief primarily resulted in social withdrawal, isolation and loneliness** on the part of participants. Participants however also noted that grief had both a positive and negative impact on their social and sexual life. Additionally, some participants seemed to recognize that there was a process that grief had on their social characterized by initial withdrawal and then the need to seek out support and self care.

Table 10 – Effect of Grief on Social and Sexual Life (21 of 25 participants identified this type of impact)	
Type of Symptom	***Number of Participants who identified this effect***
Social Withdrawal/ Isolation/ Loneliness	**10 of 21**
Loss of Sexual Libido	**2**
Improves Sex life in Intimate Long-term relationship	**1**
Increased desire for emotionally meaningless casual sex	**1**
Positive Impact on Social Life	**1**
Cancel Social/ Sex Life or greatly increase it	**2**
Participants recognized a process of initial withdrawal and then seeking out support and self care	**5**

Effect of Grief on Spiritual Life

Participants describe **primarily a positive impact on their spiritual life** as outlined in Table 11. Grief has challenged, reaffirmed and strengthened participants beliefs, created a crisis of faith, provided spiritual gifts, reduced participants' fear of death/ dying and the afterlife, helped participants become more open, focus on living and enjoying life, and spiritual versus organized religion. A few participants identified the negative impact including being stunted, angry, constant questioning of belief system, and a fear of forgetting people.

Table 11 – Effect on Spiritual Life (20 of 23 participants identified an effect)	
Type of Effect	***Number of Participants who identified this effect***
Challenges Positive Growth ♦ **Challenged Beliefs** ♦ **Crisis of faith** ♦ **Spiritual gifts** ♦ **Reaffirmed or Strengthened belief system and faith** ♦ **Not as afraid of death/dying/ afterlife** ♦ **Focus on living and enjoying life** ♦ **Increased Openness** ♦ **Focus on Spiritual versus Organized Religion** ♦ **AIDS as a teacher as an agent to point out the need for caring & connections**	**16 of 20**
Negative Impact ♦ **Anger** ♦ **Stunted** ♦ **Fear of forgetting people** ♦ **Constant questioning of belief system**	**5 of 20**

Individual and Organizational Coping

These participants describe diverse ways in which they attempt to cope with the impact of AIDS work. They also identify that grief is a central theme within this work. Tables 12 - 19 and there analysis highlight both the impaired and positive individual and organizational coping strategies from the combined questionnaire and ethnographic data. The analysis here is broken into participants' first connection and ongoing motivation for AIDS work, individual coping, and staff coping.

First Connection and Ongoing Motivation for AIDS Work

As outlined in Table 12 we see that participant's **primary connection to HIV/AIDS work is a personal experience with HIV through family or friendship**. Professional responsibilities are the next motivation for AIDS work. Volunteer responsibilities are far less a reason for participants' first connection with HIV/AIDS. However, when you examine respondents motivation **a form of deep personal or community commitment continue to be forms of primary motivation** for seventeen

of 27 individuals as Table 13 outlines. Professional commitment is expressed as the ongoing motivation in ten of 27 participants from Table 13.

Table 12 – Participants' First Connection with HIV/AIDS	
Type of Experience	***Number of participants who describe this experience***
Personal – Family/friend	**17 of 27**
Professional Responsibilities	**9 of 27**
Volunteer Responsibilities	**1 of 27**
Table 13 – Motivation for Current AIDS Work	
Description	***Number of participants who describe this experience*** **(Four participants identify more than one)**
Community Commitment	**8 of 27**
Personal Experience with HIV	**7 of 27**
Professional Commitment	**10 of 27**
Altruistic Commitment	**4 of 27**
Memorial Commitment	**1 of 27**

The ethnographic data highlights the importance of finding meaning and purpose in the work to assist with your ongoing motivation and commitment. Table 14 identifies that **meaning and purpose of the work** assist the Winnipeg regional participants with their resilience. However, this ethnographic data also tells us that balance and setting limits, family, spirituality, the quality of support of co-workers or peers, story telling and sharing, self care, hope and humor are important aspects to sustain this commitment.

Table 14 - What gets you through?
(Ethnographic data for a four agency workshop in the Winnipeg region[3])

Hope

- It's about the beginning of life.
- I believe in the treatments and that I can improve the quality of someone's life.

Meaning and Purpose

- AIDS has given meaning to my life
- Being able to use my skills keeps me challenged
- Bearing witness somehow leads to a better quality of life for me
- Knowing I make a difference, that my work has an impact
- Personal satisfaction that my work is appreciated
- Knowing people don't die alone

Family

- I can leave stuff at work as my kids need me when I get home
- Being able to be silly with my daughter
- My partner
- My kids help me maintain balance

Story telling and Sharing

- Being able to talk about my losses – not just AIDS related ones"
- Ritual, telling stories over coffee

Self Care

- Taking a break and doing something completely different.
- Monitoring my stress levels and managing stress with self-care

Balance and Setting Limits

- Having good boundaries
- I celebrate the small victories
- I make a conscious choice not to get too involved, this is just a job
- My kids help me maintain balance

Spirituality

- My faith
- The depth of contact makes me feel that I am not alone
- Real human contact helps keep me more reflective

The Quality of support of my Co-workers or peers

- I have confidence in others around me
- Being able to offer support to others
- I get solid team support

Humor

- Especially twisted

[3] Ethnographic data from pages 3-4 of a summary of group intervention #5 in the Winnipeg region.

Table 15 – Support Sought to assist with Grief (Organized in order of importance)	
Type of Support Sought	*Number of participants who sought out this type of support*
No/ Not formally/ No Comment Isolated – no one understood what it was like at work	12 of 27 1 of 27
Informal Support ♦ Family/Someone Close to Me/Partner ♦ Friends	15 of 27 (4 with using both) 8 of 27 9 of 27
Therapist ♦ Get into the grief more deeply ♦ Supportive Psychotherapy ♦ Psychiatrist ♦ Counseling ♦ Need a referral to psychologist or counselor	7 of 27
Co-Workers	4 of 27
Body Care ♦ Massage/Chiropractic/Aroma therapy ♦ Psychic Healing/Meditation	1 of 27
Literature/ Music ♦ Books/poetry/music/ writing (disembodied friends)	1 of 27
Sick Time	1 of 27
YES NOT SPECIFIED	1 of 27

Participants were also asked regarding the self-care strategies they use to assist with the demands of AIDS work. Table 16 summarized the comments of these participants. **Informal supports are a primary source of self-care** with family and partner relationships chosen first with friends then pets as forms of support for self care. Participants also set and use various forms of **activities to balance or limit the impact**

as part of their self care strategies. Various forms of time out and time away strategies are also used by ten of 27 participants. Diverse forms of body care are used in eight of 27 participants and spirituality by five of 27 participants. Participants describe cognitive approaches they use to focus on their contributions, maintain a positive outlook, and name and understand their experience. Emotional expression and co-workers are interesting only referenced once as a form of self-care strategy by three of 27 participants. Psychotherapy is used by two of 27 participants. One participant identifies that talking or story telling with a select group that understands the loss is helpful. One participant acknowledges doing a terrible job with their self care which is likely to present a challenge to them and their organization given the demands of a leadership position in the Atlantic region.

Table 16 – Self Care Strategies for AIDS Work
(Organized in order of importance)

Type of Self Care	***Number of participants who used type of support***
Loved ones	**13 of 27 (with 4 using more than 1)**
♦ **family/partner**	**11 of 27**
♦ **friends**	**6 of 27**
♦ **pet**	**2 of 27**
Activities to Balance or Limit the Impact	**13 of 27 (with 4 using more than 1)**
♦ **Don't take my work home with me**	**3 of 27**
♦ **Of time/ community commitment and responsibilities/ strict boundaries**	**5 of 27**
♦ **Knowing my strengths and limitations**	**1 of 27**
♦ **Understanding my role and purpose**	**1 of 27**
♦ **Picking my battles**	**1 of 27**
♦ **Not becoming attached to coworkers**	**1 of 27**
♦ **Balance in my daily work activities**	**2 of 27**
♦ **Balance of family/friends outside of AIDS work**	**1 of 27**

Time Out/ Time Away	10 of 27 (with 5 using more than 1)
♦ Time for self ♦ Junk day ♦ Traveling ♦ Writing ♦ Reading novels ♦ Education ♦ Singing/Music ♦ Artistic activities	8 of 27 1 of 27 2 of 27 1 of 27 1 of 27 1 of 27 2 of 27 2 of 27
Body Care	8 of 27 (2 using more than 1)
♦ Exercise ♦ Nutrition ♦ Aroma therapy ♦ Chiropractic ♦ Massage ♦ Relaxation	8 of 27 2 of 27 1 of 27 1 of 27 2 of 27 1 of 27
Spirituality	5 of 27 (3 using more than 1)
♦ Reflection ♦ Prayer ♦ Church ♦ Talking circles ♦ Psychic skills ♦ Meditation	2 of 27 2 of 27 1 of 27 1 of 27 1 of 27 1 of 27
Cognitive Approach	5 of 27
♦ Focus on positive/positive people ♦ Understanding and naming what is going on ♦ Trusting myself as capable	3 of 27 1 of 27 1 of 27
Emotional Expression	3 of 27
♦ Laughter (Humor) ♦ Cry ♦ Acknowledge fear/pain/sadness	2 of 27 1 of 27 1 of 27
Co-Workers	3 of 27
Psychotherapy	2 of 27
Talking/ sharing stories (with select group of people who knew/shared experiences with whomever is lost)	1 of 27
Terrible Job with Self care	1 of 27

Workshop participants among AIDS Coalition of Nova Scotia volunteers were expressive of "profound loss experiences"[4]. These workshop participants were asked about their resilient coping strategies. These are summarized in Table 17.

Table 17 – Resilient Coping Strategies of Volunteers at the AIDS Coalition of Nova Scotia (Ethnographic data from facilitated workshop in the Atlantic Region[5])
Artistic Expression ♦ **Writing** ➢ **Poetry** ➢ **About when my Dad died** ➢ **Fifteen minutes of "stream of consciousness" in the morning** ➢ **Journalling** ➢ **Keeping a scrap book, anything creative** ♦ **Music and Singing** ➢ **Keeping stuff down with music and singing**
Memorializing ♦ **Carrying the dead with me** ♦ **Spending time with my memories; thinking about when my Mom died** ♦ **Thinking of happy moments from the past**
Relaxation ♦ **Curling up with music and tea**
Focus on Positive Contributions ♦ **Living with a positive attitude since I cannot change my HIV status** ♦ **Focus on the work: get through today and try and change tomorrow** ♦ **Be honest: tell the truth as I see it**
Emotional Expression ♦ **Wailing in the car**

[4] A quote from page 2 of ethnographic data from Intervention #6 in the Atlantic Region.

[5] Ethnographic data from page 2 of a summary of group intervention #6 in the Atlantic region.

The ethnographic data from Table 18 reveals both the negative and positive coping of individuals and the organization. The volunteers for the AIDS Coalition of Nova Scotia as outlined in Table 17 use considerable forms of artistic expression, especially writing. This suggests that workshops or opportunities designed to encourage or share this form of expression may provide considerable healing benefit for volunteers in this region.

Staff Coping

The facilitated regional group interventions also solicited data about coping. The responses thus far from the Atlantic region are organized into themes. The data from Table 18 was solicited from seven Executive Directors and one support worker in the Atlantic region in response to the question – 'how are you and your staff coping'.

Table 18 – How are you and your staff coping?
(Ethnographic data from facilitated workshop in the Atlantic Region[6])

Negative Coping	*Positive Coping*
Poor Self Care ♦ **Alcohol** ♦ **Smoking** ♦ **Overworking**	**Sharing** ♦ **Peer support outside the workplace** ♦ **Debriefing sessions taking the format: "What will you miss about "X", What will you not miss about "X".** ♦ **Weekly staff meeting including a check-in and information sharing sessions to help cope with a range of issues including: the emerging IDU population, young women (under 23) with HIV, youth infections in general.**
Emotional or Physical Withdrawal and Shutting Down ♦ **Withdrawal behind closed doors** ♦ **Denial, "I'm fine"; refusing to accept the legitimacy of grief (this is not the work)** ♦ **Desensitization (numbing)** ♦ **Inaction, "I know what I need, I just can't do it"**	**Memorializing** ♦ **Memorials open to all connected workers** ♦ **"Living Wakes"** ♦ **The Quilt panels** ♦ **A memorial wall, book and lit candle** ♦ **The community AIDS memorial** ♦ **Honoring the legacies**

[6] Ethnographic data pages 2-3 from a summary of group intervention #1 in the Atlantic region.

Table 19 – Coping Of Staff:
Comparison Of AIDS Work In Three Organizational Contexts

VANCOUVER REGION

- ***Some improvement but others still have impaired self care* (V2) (V1) (V3) (V7)**
  - Union has a role it can play **(V1)**
  - We talk a lot about it **(V5) (V9)**
  - Some people do not seem to give themselves permission for self care **(V7)**
  - Staff look ill and it is difficult to witness this **(V8)**
  - Staff want to be taken care **(V8)**
  - Negativity or finger pointing/ not much care **(V4)**
  - Job shares **(V9)**
  - Stress Leaves **(V9)**
- **Blank (V6)**
-

MANITOBA REGION

- ***Impaired Self Care (W7)***
  - Overworking **(W1,W2) W10**
  - Isolation – Don't seem able or allowed by confidentiality to share **(W3)**
  - Burnout due to long hours, high level output, few boundaries **W7,W9**
  - Some staff lash out or displace at other staff (**W10)**
- ***Self Care and Supporting each other* (W2)**
  - Time away with family **(W6)**
  - Physical activity – exercise **(W8)**
  - Group socialization – partying **(W3, W5, W6)**
  - Consciousness around self care needs **(W10)**
  - Distance from one another outside of work **(W7)**

No comment (W4)

ATLANTIC REGION

- ***Impaired self care* (AED1)**
  - Overworking
  - On the road to burnout **(AED4)**
- ***Self care and supporting others***
  - *Meditation* **(AED5)**
  - Taking time for themselves **(AED3)**
  - Supporting Each Other
  - Family support **(AED5) (AED5) (AED1)**
  - Talking with one another **(AED5) (AED1)**
  - Talking circles **(AED3)**
  - Folks consciously taking it easy on themselves **(H3)**

Blank (H1) AED2 missing

Table 20 – Current Grief/ Loss Issues: Comparison of Grief In Three Organizations Contexts

VANCOUVER REGION

- ***Change/Transition/Unresolved Grief*** (V8)
  - Population being served (V4)
  - Loss of credibility and impact in the community (V4)
  - Loss of connection to the community where we began (V9)
  - Healing old wounds and supporting each other (V7)
- ***Multiple Loss/ Uncertain future***
  - Drug Cocktails create brief respite but deaths beginning again (V5)
- ***Impaired Care and Communication***
  - Poor communication during times of stress, emotional volatility and organizational change (V1)
  - Top down decision making
  - Loss of Energy and Vitality (V9)
  - Frequent staff turnover (V8)
  - Work overload (V8)
  - Diminished Teams (V8)
- Blank (V6) (V3)

MANITOBA REGION

- ***Change/Transition***
  - Changing mandate (W1)
  - Organizational Transition (W3,W7)
  - New Executive Director again (W4,W6)
  - New Location (W4,W5, W6, W8)
  - Uncertain organizational future (W1)
  - Learning how to trust and creating a safe environment (W3)
  - Limited sense of stability constant state of crisis (W10)
  - GayLesBi Organizations are becoming even more mainstream (W5)
  - New clientele (W1)
  - Large staff turnover (W1)
- ***Climate of Grief***
  - Others grieving (W2)
  - Clients who are HIV+ (W2)
  - News from colleagues in other ASO's (W2)

ATLANTIC REGION

- ***Coping with Unresolved Grief Issues***
  - Causing some board members to focus on the financial aspect of AIDS instead of client needs (AED5)
  - Being able to move on and not stay focused on losses (AED1)
  - Living with Hope rather than with grief (AED1)
  - Return to more loss after brief reprieve with new drug cocktails (AED4)
  - A need to develop coping strategies for dealing with deaths (AED1)
  - Loss of Staff due to Burnout (AED3)
  - Death of a Member (H2) (H3)
- ***Change in organizational approaches***
- Blank (H1), AED2 MISSING

Table 21 – Emerging Needs In AIDS Work:
Comparison Of AIDS Work In Three Organizational Contexts

VANCOUVER REGION

- ***Changing Demographics and its impact on Organization Development* (V2, V5) (V3)**
  - Serving a new group when our programs are severely outdated **(V4)**
  - Diversity of populations accessing services **(V1)**
  - Conflicts re: priorities **(V1)**
  - Former/founding populations finding it hard to continue accessing services at AIDS Vancouver because we are providing services to a new group **(V4)**
  - Uncertain direction and strategies to intervene **(V6)**
  - Micromanaged services by gay mean and for gay men **(V6)**
  - To work as an unfractured team on a big issue **(V8)**
  - Blandness of people's responses now to AIDS **(V9)**

MANITOBA REGION

- ***Changing Demographics and it's impact on Organizational Development***
  - Addictions – IDU **(W1)**
  - HIV+ Women's Issues **(W1)**
  - Aboriginal Issues around HIV **(W1)**
  - Adequately respond to the diverse groups of people affected by HIV **(W6)**
  - Culturally appropriate services **(W6)**
  - Volunteers – when should we be recruiting new volunteers **W1**
  - Being able to do prevention and education work with other agencies so we as ASO's don't become so territorial **(W6)**
- ***Organizational and Political Transition (W7)***
  - What are the political issues? **(W1)**
  - Collaboration as Aboriginal with non Aboriginal ASO's and funders **(W2)**

ATLANTIC REGION

- ***Changing Demographics***
  - Connecting with emerging populations **(AED1)**
- ***Supporting chronic versus terminal ill clients (AED5)* (AED1)**
- ***Inadequate human and financial resources to serve***
  - A primarily rural region **(AED4) (AED2)**
  - Secure Operational Funding **(AED3)**
- ***HIV/AIDS Prevention still needed* (AED1)**
- ***Change*** *(perceptions, our world, technology, government, board, treatments* ***(H3)***
- ***Informing new and old members what we can do for them (H2)***
- **Blank (H1)**

- Clinging to certain demographics solely to continue funding needs **(V9)**
- ***Grief (V2)***
  - To maintain wholeness in this work **(V8)**
  - Supporting each other **(V7)**
  - Understanding and acceptance of differing work **(V7)**
- ***Provincial Politics V2) and Resources***
  - Staff **(V2)**
  - Uncertain funding **(V1)**
  - Increasing skills and knowledge required by workers **(V1)**
  - Double the clients in past four years with no new provincial dollars **(V3)**
  - Building Partnerships **(W7)**
  - Integrating with other agencies **(W3)**
- ***Resources***
  - Funding and Resources **W7,W4,W8,W10**
  - Continual striving for funding not conducive to long-term planning and reinforces ASO's state of crisis **(W10)**
  - Burnout among colleagues **(W7)**
- ***Safety***
  - What are the safety issues? **(W1)**
- ***Approach of Medicine***
  - Structure of medicine destructive to the approach to promote overall health **(W9)**

Blank W5

Table 22 – Unique Provincial Context:
Comparison Of AIDS Work In Three Organizational Contexts

VANCOUVER REGION

- ***Challenge to Collaborate with Other organizations***
  - Territorial Organizations **(V2)**
  - Collaboration between AIDS people and workers needed **(V2)**
  - Unorganized disaster **(V4)**
  - History of our agency **(V8)**
  - Regionalization of HIV/AIDS responsibility from province to local level **(V3)** which means haves and have nots **(V7)**
- ***Large Client Population***
  - HIV+ saturation **(V8)**
  - Large IDU population ***(V5,V8)*** **(V1) (V9)**
- ***Resources***
  - Untrained, undertrained or unready worker's and agency **(V8)**
  - BC Centre for Excellence in HIV and Pediatric **(V1) (V5)** and Women's HIV specialists **(V1)**
  - Health care System better than some other provinces **(V5)**
  - Rural versus urban resources **(V9)**
- **Blank (V6) (V7)**

MANITOBA REGION

- ***Changing Epidemiology while there is a Loss of Resources and Supportive Political Environment for AIDS work (W1)*** **W3**
  - 1996 AIDS Strategy has yet to be implemented **(W1)**
  - Provincial government unwilling to take provide leadership **W3**
  - Small caregiving community **(W9)**
- ***Responding to Aboriginal Communities***
  - Large aboriginal population who are disproportionately at risk for HIV **(W9,W6)**
  - Speaking and AIDS workshops in Aboriginal Communities **(W2)**
- ***Organization Focus***
  - Community health with a sub specialty in HIV prevention, education, care and treatment

ATLANTIC REGION

- ***Challenges supporting diverse primarily rural population***
  - Confidentiality **(AED5)**
  - Serving all native communities in the Atlantic Region **(AED3)**
  - Social isolation of HIV/AIDS population **(AED1) (AED2)**
  - Supporting and helping closeted nature of gay clients connect with each other **(AED1)**
  - Bilingual Population **(AED1)**
- ***Inadequate funding –*** no provincial government funding **(AED1)**
  - **Blank (H1,2,3) (AED4)**

Appendix IV   Regional Resource Person Job Description

The goal for the position of Project SUSTAIN Regional Resource Person is that local consultants act as ongoing support to ASOs in addressing issues of grief, multiple loss and transition.

Basic Qualifications to function in this role include:
- Good grief counselling and chronic stress management skills, including an ability to support workers in 'grief hot spots' and in their use of healthy coping strategies.
- Knowledge of grief and multiple loss theory and of HIV/AIDS.
- Ability to assist agencies to recognize and value the natural coping strategies of staff and support the creation of effective new supports.
- Experience and knowledge of community-based organizations and the complex factors of transition.
- Basic understanding of integrating a holistic framework into both individual and organizational work.
- Ability to develop and facilitate organizational interventions which help identify and mitigate grief stressors and address the depletion of workers.
- Ability to formulate recommendations and consult with the management of as ASO to develop strategies to address staff issues related to grief and loss.
- Willingness to participate in the four-day Facilitator's Training in Toronto, in September, 2001.

Related priorities for this position include, that the Resource Person:
- Provide support to the ASO in a culturally-appropriate manner.
- Support the expansion of grief and loss support services in the agency, by presenting recommendations to the Executive Director, based on direct work with staff.
- Be informed of relevant bereavement and organizational development supports to support working linkages for ASO staff into the broader community.
- Fulfill the 'Regional' component of the work, by responding to interest from other ASOs or AIDS-related agencies for group interventions.

Training and Support

In order for the Resource Person to fulfill this role, they will engage in a mentoring process with the SUSTAIN national consultants, Yvette Perreault and Derek Scott, from the AIDS Bereavement Project of Ontario. As outlined below, Project SUSTAIN will provide training and support in AIDS-specific grief and bereavement theory and group interventions. The direct reporting relationship for the regular activities of the Resource Person will be to the Executive Directors of the pilot agencies that they work with.

Project SUSTAIN facilitators will:
- Help match the skills of the Resource People with the needs of the pilot agency.
- Support skills exchange with Resource People.
- Provide written materials to support the work, such as assessment tools and information packages.
- Develop, coordinate and finance a four-day Facilitator's Training.
- Be available for phone consultation, intervention design and support and de-briefing.