

# **PROJECT SUSTAIN:**

## **CREATING AND REINFORCING ORGANIZATIONAL SUPPORTS FOR ASO WORKERS COPING WITH THE IMPACT OF MULTIPLE LOSSES**

### **GOALS**

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

### **PROJECT PARTICIPANTS**

- ❖ VANCOUVER
- ❖ WINNIPEG
- ❖ ATLANTIC – HALIFAX
- ❖ PROJECT FACILITATORS – YVETTE PERREAULT & DEREK SCOTT
- ❖ EVALUATOR – VAL GERVAIS
- ❖ PROJECT SUPPORTS - AIDS BEREAVEMENT PROJECT OF ONTARIO
- ❖ PROJECT FUNDER – HEALTH CANADA – Canadian Strategy on  
HIV/AIDS

## **PROJECT PHILOSOPHY AND APPROACH**

### **❖ COLLABORATION**

**BETWEEN TASK FORCE MEMBERS – ABPO  
(AIDS BEREAVEMENT PROJECT OF ONTARIO)  
AND REGIONAL REPRESENTATIVES)**

### **❖ INSIDER RESEARCH**

**(USING KNOWLEDGEABLE COMMUNITY-BASED ASO TASK  
FORCE MEMBERS, FACILITATORS AND EVALUATOR)**

### **❖ ETHNOGRAPHIC RESEARCH APPROACH**

**(BASED UPON GERVAIS' 1998 QUALITATIVE STUDY OF  
AIDS GRIEF AND MULTIPLE LOSS WITHIN AN ASO)**

### **❖ QUANTITATIVE AND QUALITATIVE RESEARCH METHODS**

**(MODIFIED VERSION OF QUESTIONNAIRE USED FOR THE AIDS  
BEREAVEMENT PROJECT OF ONTARIO 1998 EVALUATION OF SUPPORT  
WORKERS)**

**(ETHNOGRAPHIC CASE NOTES OR ANALYSIS OF WRITTEN REPORTS OF  
REGIONAL ACTIVITIES)**

**(IDENTIFY AND COMPARE THEMES BETWEEN REGIONS)**

**(ANALYSIS OF EVALUATION QUESTIONNAIRE)**

**(FEEDBACK AND DISCUSSION WITH TASK FORCE AND REGIONAL PARTICIPANTS)**

## **PROJECT SUSTAIN ACTIVITIES ACROSS REGIONS**

- ❖ EDUCATION REGARDING GRIEF AND ORGANIZATIONAL TRANSITION  
TO STAFF AND BOARD**
- ❖ INDIVIDUAL AND GROUP INTERVENTION TO ASSIST WITH  
IDENTIFICATION AND BEGIN HEALING LOSSES**
- ❖ STRATEGY AND LOCAL RESOURCE IDENTIFICATION AND  
DEVELOPMENT**

**Table 1 – Project Sustain Activity and Evaluation Data Summary**

<b>TYPE OF ACTIVITY</b>	<b>VANCOUVER</b>	<b>WINNIPEG</b>	<b>ATLANTIC</b>	<b>TOTAL</b>
<b>Workshop</b>				
<ul style="list-style-type: none"> <li>• <b>Number of workshops</b></li> <li>• <b>Number of participants</b> (Includes participants who participated in more than one workshop)</li> </ul>	<p><b>21</b></p> <p><b>193+</b> (participants from the closure workshops for each visit are missing from this total)</p>	<p><b>6</b></p> <p><b>103</b></p>	<p><b>6</b></p> <p><b>44</b></p>	<p><b>33</b></p> <p><b>340+</b></p>
<b>Number of Individual Consultations</b> (on the regional site with Project Sustain Facilitators)	<b>37</b>	-	<b>5</b>	<b>42</b>
<b>Meetings/Consultations with</b>				
<ul style="list-style-type: none"> <li>• <b>ASO Management</b></li> <li>• <b>Local Resource Person</b></li> <li>• <b>ASO Board</b></li> <li>• <b>Funders</b></li> <li>• <b>Community Group</b></li> </ul>	<p><b>4</b></p> <p><b>14</b></p> <p><b>1</b></p> <p>-</p> <p><b>3</b></p>	<p><b>2</b></p> <p>-</p> <p><b>1</b></p> <p>-</p> <p><b>1</b></p>	<p><b>4</b></p> <p><b>4</b></p> <p><b>2</b></p> <p><b>1</b></p> <p><b>1</b></p>	<p><b>10</b></p> <p><b>18</b></p> <p><b>4</b></p> <p><b>1</b></p> <p><b>5</b></p>
<b>Evaluation Data</b>				
<ul style="list-style-type: none"> <li>• <b>Survey Questionnaire</b></li> <li>• <b>Ethnographic Case Notes or Visit Summaries</b></li> <li>• <b>Final Evaluation Questionnaire</b></li> </ul>	<p><b>9</b></p> <p><b>3</b></p> <p><b>2</b></p>	<p><b>10</b></p> <p><b>3</b></p> <p><b>6</b></p>	<p><b>8</b></p> <p><b>3</b></p> <p><b>5</b></p>	<p><b>27</b></p> <p><b>9</b></p> <p><b>13</b></p>
<p>* Note 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.</p>				

## FINDINGS ACROSS REGIONS

### ❖ **COMPLICATED GRIEF**

is observed in ASO workers characterized by **UNRESOLVED** personal, professional and organizational **LOSSES**

### ❖ ASO workers are **PHYSICALLY** and **SOCIALLY**

- **FATIGUED**
- **INADEQUATE SLEEP**
- **PHYSICALLY IN PAIN** – Especially Headaches, Back/Neck Pain As A Primary Symptom Identified With Grief
  - **OVERWORKING**
  - **ISOLATED**

Due To AIDS Grief And Multiple Loss And The Energy Demands Of AIDS Work, ASO workers are:

### ❖ **EMOTIONALLY** Experiencing

- **SADNESS OR DEPRESSION**
  - **NUMB**
  - **ANXIOUS**
  - **ANGRY**
  - **TEARFUL**

### ❖ **ORGANIZATIONALLY** Experiencing

- **STAFF TURNOVER AND BURNOUT**
  - **IRRITABILITY**
  - **EMOTIONAL OUTBURSTS**
- **CO-WORKERS ARE NOT USED AS FREQUENTLY AS EXPECTED**
- **GRIEF HAS NEGATIVE IMPACT ON CARE AND COMMUNICATION WITHIN AN ASO**
  - **DENIAL OF OR UNAWARE OF IMPACT OF GRIEF**

ASO WORKERS ARE ALSO COPING WITH ONGOING  
*ADDITIONAL ORGANIZATIONAL CHALLENGES*  
ALONG WITH AIDS GRIEF AND THESE ARE:

- ❖ **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 CLIENT NEEDS ARE MORE COMPLEX AND DIVERSE**

ASO WORKERS ALSO IDENTIFY THE  
***POSITIVE IMPACT OF AIDS WORK*** AND **THEIR**  
***POSITIVE COPING STRATEGIES***

- ❖ **POSITIVE IMPACT ON SPIRITUAL GROWTH**
- ❖ **BALANCED COMMITMENT TO THE WORK**
- ❖ **PERSONAL OR COMMUNITY COMMITMENT CONTRIBUTES TO MEANING AND PURPOSE OF THE WORK**
- ❖ **CREATIVITY WITHIN AN ASO AN ESSENTIAL PART OF INDIVIDUAL AND ORGANIZATIONAL RESILIENCY**
- ❖ **THE MAJORITY OF PARTICIPANTS USE INFORMAL CARE STRATEGIES**
- ❖ **THESE RESILIENT SELF CARE STRATEGIES INCLUDE:**
  - **BALANCE AND SETTING LIMITS**
  - **TIME OUT OR TIME AWAY**
  - **QUALITY OF SUPPORT OF CO-WORKERS OR PEERS**
  - **FAMILY/FRIENDS**
  - **SELF AND BODY CARE**
  - **STORY TELLING**
  - **HOPE & HUMOR**
- ❖ **PSYCHOTHERAPY IS THE PRIMARY FORMAL CARE STRATEGY**

## **REGIONAL COMPARISON**

<b>VANCOUVER</b>	<b>WINNIPEG</b>	<b>ATLANTIC</b>
<ul style="list-style-type: none"> <li>➤ YOUNGEST WORKERS WITH LEAST PAID AND UNPAID EXPERIENCE</li> <li>➤ LARGEST NUMBER OF PROFESSIONAL AND SECOND LARGEST ACQUAINTANCE DEATHS</li> <li>➤ ORGANIZATIONAL MISTRUST AND INTERNAL CONFLICT</li> <li>➤ INCREASING THEMES OF NEGATIVITY AND BURNOUT</li> <li>➤ EROSION IN ORGANIZATIONAL RESOURCES &amp; CHALLENGE TO WORK MORE COLLABORATIVELY BETWEEN OTHER ORGANIZATIONS</li> <li>➤ LARGEST IDU COMMUNITY AND SIZE AND DIVERSITY OF CLIENT POPULATION</li> <li>➤ BEGAN WORK WITH LOCAL RESOURCE PERSON</li> <li>➤ PROJECT SUSTAIN ACTIVITIES HELPED ADDRESS SOME OF THE IMPAIRED COMMUNICATION PATTERNS WITHIN THE ASO AND STIMULATED WORKING TOWARD A HEALTHY ORGANIZATIONAL CULTURE</li> <li>➤ REGIONAL LEADERSHIP AND PARTNERSHIP TO CARRY ON THIS WORK</li> </ul>	<ul style="list-style-type: none"> <li>➤ INDIVIDUALLY AND ORGANIZATIONALLY THE MOST RESILIENT AND RESOURCEFUL IN RELATION TO THE YEARS OF HIV WORK</li> <li>➤ OVERWORKING IS PRIMARY COPING MECHANISM</li> <li>➤ MOST LIKELY TO EXPERIENCE THE LOSS OF A FAMILY MEMBER OR CO-WORKER</li> <li>➤ LARGEST NUMBER OF ACQUAINTANCE DEATHS</li> <li>➤ LARGE ABORIGINAL COMMUNITY PRESENTS AS A PRIMARY CHALLENGE</li> <li>➤ THE AMALGAMATION OF FOUR AGENCIES PREOCCUPIES THE CONCERNS AND ENERGIES OF THIS REGION</li> <li>➤ IDENTIFIED A LOCAL RESOURCE PERSON AT THE END OF THIS PHASE OF THE PROJECT</li> </ul>	<ul style="list-style-type: none"> <li>➤ OLDEST AND MOST EXPERIENCED WITH PAID AND UNPAID AIDS WORK</li> <li>➤ CLIMATE TENTATIVE TO SHARE THE IMPACT OF AIDS GRIEF</li> <li>➤ LACK OF OR AMBIVALENT AND/OR RECOGNITION OF THE IMPACT OF GRIEF BY BOARD MEMBERS</li> <li>➤ LARGELY RURAL REGION CHALLENGES ORGANIZATIONS TO PROVIDE SERVICES, PROTECT CONFIDENTIALITY, AND ASSIST CLIENTS TO CONNECT WITH EACH OTHER</li> <li>➤ INTEGRATED A LOCAL RESOURCE PERSON FROM THE BEGINNING WITH PROJECT SUSTAIN</li> <li>➤ INITIATED A STRATEGIC PLAN TO RESPOND TO THE ISSUE</li> </ul>

## **FUTURE RECOMMENDATIONS**

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