Grandmothers to Grandmothers: THE DAWN OF A NEW MOVEMENT

THE STORY OF THE GRANDMOTHERS’ GATHERING
AUGUST 11 - 13, 2006, TORONTO, CANADA
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The Stephen Lewis Foundation (SLF) helps to ease the pain of HIV/AIDS in Africa at the grassroots level. It provides care to women who are ill and struggling to survive; assists orphans and other AIDS-affected children; supports heroic grandmothers who almost single-handedly care for their orphan grandchildren; and supports the remarkable efforts of associations of people living with HIV and AIDS.

www.stephenlewisfoundation.org

The Grandmothers’ Gathering was hosted by the Stephen Lewis Foundation as part of the Grandmothers to Grandmothers Campaign. The campaign aims to: raise awareness in Canada about Africa’s grandmothers and their struggle to secure a hopeful and healthy future for generations of children orphaned and made vulnerable by HIV/AIDS; build solidarity amongst African and Canadian grandmothers; and actively support groups of grandmothers in Africa by providing them with much-needed assistance.

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This is a tribute to Grandmothers from Africa, who have humbled us with their super-human responses to unbearable sorrow and hardship, and to Grandmothers from Canada, who have inspired us by reaching across continents to lighten the loads of strangers.

Since the Stephen Lewis Foundation (SLF) was started in March 2003, thousands of individuals have sent donations of all sizes, allowing us so far to fund over 170 projects in 14 of the most HIV-affected countries in sub-Saharan Africa. In direct partnership with struggling grassroots and community-based organizations, we can now support women and children orphaned by AIDS and ameliorate some of the pain suffered by people whose modest dreams have been shattered by this pandemic.

In the last year, though, whenever my father, Stephen Lewis, returned from a trip to Africa, he seemed especially haunted by two impressions: first, of the unnatural paucity of young women everywhere, and second, by the droves of older women, wearied and worried by loss and poverty and the back-breaking work of caring for their orphaned grandchildren. At the same time, as we poured through incoming grant proposals at the Foundation, we noticed mounting references to caregivers and their special needs — and when we probed further, our suspicions were confirmed. Africa’s rural villages and urban slums were teeming with older women who had nursed and then buried their own children, had been pummeled by poverty and despair, and had somehow found the courage and energy to become parents all over again — this time, to a generation of bereft, confused youngsters. One extended family at a time, a continent in tatters was being stitched back together by grandmothers.

We investigated further and discovered that, although a trend had clearly exploded into a phenomenon, very few organizations were paying attention. HelpAge International was one notable exception, and we drew heavily on their information and expertise as an idea took form. Here and there in Africa, we were learning, grandmothers struggling with similar hardships had begun to meet regularly to support and sustain one another. Meanwhile, a growing number of empathetic Canadians — women whose hearts had been touched because they knew firsthand of grandmotherly love and grandmotherly challenges — had also formed groups with the aim of sending help to their unknown sisters across the Atlantic. The Canadian grandmothers were eager to find out what kind of help was most needed, and the African grandmothers barely had the time or resources to attend their support group meetings, much less to guide potential benefactors overseas. A need was obvious. A movement seemed possible.

We wanted to give African grandmothers a forum to speak about their lives, voice their concerns and help inform the international support that can and must come. We wanted to give Canadian grandmothers the chance to hear that testimony in person. And we wanted to offer both groups the opportunity to become acquainted, to pool their knowledge and wisdom, influence, creativity, insights, commitment and determination, and just possibly to plot an end to the suffering together.
Thus was born the idea of the Grandmothers to Grandmothers Gathering. On the eve of the XVI International AIDS Conference, 100 African grandmothers affiliated with Foundation-supported projects arrived in Toronto, with their project facilitators, from Kenya, Malawi, Mozambique, Namibia, Rwanda, South Africa, Swaziland, Tanzania, Uganda, Zambia and Zimbabwe, and were met by 200 self-funded grandmothers from across Canada. They had come to take part in over 40 workshops on topics ranging from grief to traditional songs, orphan care, depression and fundraising — each one designed, selected and run by the grandmothers themselves — as well as to sing, dance and try new foods, share photographs of their loved ones, cry, laugh, hug, pledge and promise, shake their fists, clench their teeth, talk to journalists, pose for pictures, and march through the streets of Toronto. They had come to speak, and listen, and start a movement.

This report attempts to capture what occurred during two and a half intensely emotional, energized, exhausting, exhilarating days. We haven’t tried to produce an exhaustive account of the situation of Africa’s grandmothers or to draw definitive conclusions here. We have tried instead to bear witness.

The work of countless committed friends and supporters in Canada and Africa made the Grandmothers to Grandmothers Gathering a success beyond our wildest imaginings, covered in hundreds of newspaper, TV and radio stories throughout Canada and the world, from the New York Times to London’s Guardian, CNN, Reuters and the BBC. On the eve of International Women’s Day 2006, when we launched the campaign, there were just a few grandmothers’ groups in Canada. By the time of the Gathering there were almost 50, and today there are over 140 active groups — with that number growing steadily. Grandmothers’ groups in Africa are also proliferating, and making themselves audible and visible as never before. Their newfound support is allowing growing numbers of grandy groups to generate income, cope with loss and grief, organize, lobby for access to treatment for their grandchildren and themselves, and change national policies. The following pages demonstrate how, out of Africa’s courage and Canada’s generosity, a Grandmothers’ Movement was born. We are honoured to be part of it.

Ilana Landsberg-Lewis, Executive Director

© Tamai Kobayashi
May this be the dawn of the grandmothers’ movement.
On August 13, 2006, African and Canadian grandmothers delivered a message to the world. The ‘Toronto Statement’ is the culmination of the key points from the Grandmothers’ Gathering. It was presented to representatives from UNAIDS and the XVI International AIDS Conference at the close of the Gathering.
As grandmothers from Africa and Canada, we were drawn together in Toronto for three days in August 2006 by our similarities: our deep love and undying devotion to our children and grandchildren; our profound concern about the havoc that HIV/AIDS has inflicted on the continent of Africa, and in particular on its women and its children; and our understanding that we have within us everything needed to surmount seemingly insurmountable obstacles. We are strong, we are determined, we are resourceful, we are creative, we are resilient, and we have the wisdom that comes with age and experience.

From one side of the globe we are African grandmothers from Kenya, Malawi and Mozambique; from Namibia, Rwanda, South Africa and Swaziland; from Tanzania, Uganda, Zambia and Zimbabwe, raising the children of our beloved late sons and daughters. We come to the end of this historic gathering filled with emotions: we are grateful for the chance we have been given — at last — to make our voices heard. We are relieved to have had an opportunity to tell our stories, to share our experiences, to describe our hardships and our pain, to share the anxieties and express the sadness that descended on us late in our lives, and to receive respectful acknowledgement for the ongoing grief that scars our daily existence.

Each of our stories is different, each of our experiences is unique, and yet we are here as representatives of countless women who share in our tragedy: for every grandmother here today, there are fifty, sixty, seventy thousand at home. We have needs today, needs for the short-term and needs that will never go away. It is our solemn duty to the millions of grandmothers whose voices have never been heard that gives us the courage to raise those needs to demands — on their behalf, and on behalf of the children in their care.

Today, we demand the ear of the powerful: these words are for the conference.
organizers and the 25,000 delegates assembled at the 16th International AIDS Conference; for its host government, Canada; for the Global Fund to Fight AIDS, TB and Malaria; and for the United Nations. Grandmothers are worth listening to. We demand to be heard.

In the short-term, we do not need a great deal, but we do need enough: enough to safeguard the health of our grandchildren and of ourselves; enough to put food in their mouths, roofs over their heads and clothes on their backs; enough to place them in school and keep them there long enough to secure their futures. For ourselves, we need training, because the skills we learned while raising our children did not prepare us for parenting grandchildren who are bereaved, impoverished, confused and extremely vulnerable. We need the assurance that when help is sent, it goes beyond the cities and reaches the villages where we live. In the long term, we need security. We need regular incomes and economic independence in order to erase forever our constant worry about how and whether our families will survive.

We grandmothers deserve hope. Our children, like all children, deserve a future. We will not raise children for the grave.

From another side of the globe, we are Canadian grandmothers, arriving at the end of our gathering enlightened, resolved, humbled and united with our African sisters. We stand firm in our commitment to give of ourselves because we have so much to give — so many resources, such a relative abundance of time, so much access, so much influence, so much empathy and compassion. We recognize that our African friends are consumed each day with the business of surviving, and so we have offered — and they have accepted — the loan of our voices. We pledge to act as their ambassadors, raising the volume on their long-suppressed stories until they are heard, understood and acted upon. We promise to apply pressure on governments, on religious leaders, and on the international community. We are committed to mobilizing funds, and recruiting more ambassadors among our sisters in Canada. We are dedicated to finding ways to make it clear that Africa’s grandmothers hold a place in our hearts and in our thoughts not just today, but each day. We are acutely conscious of the enormous debt owed to a generation of women who spent their youth freeing Africa, their middle age reviving it, and their older lives sustaining it. We will not rest until they can rest.

Africans and Canadians alike, we arrived at our grandmothers’ gathering with high expectations, but also with nagging apprehensions. We worried that the grief — our own and our sisters’ — would be overwhelming. We harboured fears that the language barriers would separate us. We Canadian grandmothers worried that our capacity to help might be reduced to fundraising alone; we African grandmothers worried that our dire straits might cast us as victims rather than heroes. But we were motivated to make the trip by the special love that every grandmother knows, and we were emboldened to face our fears by the wisdom of our years. Our courage paid off. The age-old African ways of speaking without words broke down our communications barriers. We gestured and nodded. And we sang. We danced. We drummed. We laughed and clapped and wept and hugged. Through our new discovery — grandmother to grandmother solidarity — we carried ourselves and one another through the grief to where we are this morning.

May this be the dawn of the grandmothers’ movement.”

Toronto, Canada, 13 August 2006
“We hope that Canadian grandmothers will recognize our strength — the spirit of ‘ubuntu’ — taking care of each other. We have experience in activism and advocacy, we know what to do and what we need… give us the support and we will show you what we can do!”
The Grandmothers’ Gathering began with workshops in which African and Canadian grandmothers met separately. “Talking About Solidarity” gave both groups (in all their internal diversity) the chance to meet amongst themselves and talk about their expectations, hopes and concerns about the upcoming two days’ worth of intensive and interactive workshops. The work of building solidarity with each other and across continents required a common understanding and common ‘language’, and this section tries to capture the insights the grandmothers shared and the challenges they surmounted. The staff and volunteers of the Stephen Lewis Foundation (SLF) were unanimous in our realization, as we witnessed the proceedings, that both groups exhibited exceptional grace, mutual support and love, as they began to build a movement together.

The African grandmothers raised a number of similar issues as they set the stage in the opening sessions: a desire to create networks amongst themselves, to learn about the Canadian grandmothers, and to determine how they could work together to create awareness and generate financial support. They expressed an urgent desire to be heard and tell their stories, and a commitment to continue to speak out and garner support because they felt a deep sense of responsibility to thousands of other grandmothers in Africa who, like them, are struggling with the effects of the pandemic.

The theme of ‘strength in unity’ resonated throughout. The African grandmothers’ sentiment, “You can’t break us when we are together” was embraced by all. One group described its metaphor of fashioning a quilt from scraps of garbage, or “making something out of nothing,” as they do when they come together to develop community projects with day-care, gardens, feeding programmes and income-generating schemes. GAPA — the Grandmothers Against Poverty and AIDS from South Africa — took this analogy further, demonstrating how they use a patchwork quilt as a symbol of a grandmother who has had to remake herself after losing everything; by working with other grandmothers, a strong whole is reconstructed from an individual whose life has been torn apart. Other African grandmothers brought a bunch of small sticks and showed how one stick alone is easy to snap, two sticks together are harder, and three or more bundled together are unbreakable.

Everyone assembled was determined to keep African grandmothers’ voices front and centre. A strong theme that emerged from the solidarity workshops was that the African grandmothers should set the agenda and determine the kind of support to flow from the Gathering. A sense of unity was established early, generated by the shared intent to offer a forum, legitimacy and respect to a legion of older women in Africa from whom the world has never heard directly. The grandmothers from Africa often described their personal journeys from grief, suicidal thoughts, immobility and isolation to becoming community organizers in their villages and role models of survival and hope.
for both their sisters and grandchildren. They have become agents of change, bringing a wealth of experience, compassion and skills to an indescribably complex problem, and a deep understanding of the solutions that are needed. They lack only the resources and support to deal with the devastation caused by their losses — all of them have lost children, and some have lost multiple children, spouses, siblings and orphaned grandchildren. They described their fundamental need for funds to feed and educate their grandchildren and to provide them with adequate shelter. They also spoke of their need for support to break through the stigma and discrimination they all keenly felt.

Some participants may have arrived assuming that the African grandmothers were victims without the skills to improve their situations. Everyone left thinking of them as resilient and courageous women, open about their hardship and their journey from agony to survival, joyous in their appreciation of life and the opportunity to learn and share their thoughts. It was impossible not to be inspired and moved by them.

“If we agree with each other that ‘old is gold’, then what should be done to rescue these grandmothers from this nightmare?”

At the same time, we heard of the enormity of the challenges the African grandmothers face, including:

- Their fears about the death surrounding them;
- The hardship and uncertainty of those caring for children who are HIV-positive;
- The pervasive crisis of hunger;
- Their lack of adequate shelter and the constant threat of homelessness;
- The need for steady incomes and income-generating programmes;
- The desperate need for psychosocial support for both the adults and their grandchildren;
- The deep fear that nothing would change to break through the stigma around HIV/AIDS, and that the cycle...
of infection and death would continue into the next generation;

- The need for adequate pensions;

- The urgent need for the schooling that could secure a future for their grandchildren — from the abolition of school fees and beyond, to money for books, shoes, pencils, uniforms and test fees;

- The essential need to have space and a place to grieve, including ongoing support groups and programmes for both the women and their grandchildren.

“I had lost hope but now I have hope again from this weekend. I feel big again... we have not been forgotten”

Canadian grandmothers discussed their apprehension about how to bridge the gap between their own experiences and those of the African grandmothers, and expressed their worries about the language barriers, the cultural divides and the diversity of ideas from Canadians about how to respond. The idea of establishing networks in Canada that could provide support through fundraising, advocacy and education was raised in several groups. The Canadian grandmothers said they had come into the Gathering determined to assist in meaningful and concrete ways, but then wondered over and over again — how was this to be achieved? Fears about raising hopes and expectations and then failing to deliver were expressed in several workshops, as was a commitment to maintain the energy of the Gathering and succeed in keeping grandmothers on the agenda at local and national levels. No one wanted mere talk; action was on everyone’s mind.

“We need to establish a sense of reciprocity with our African sisters. They need to know that they are our inspiration, that we both are getting something from this relationship.”

Canadian grandmothers wanted to learn from one another and from the African grandmothers — and to leave with clear ideas about how to make their response tangible and meaningful for their African counterparts. The Canadian workshops discussed ideas about networking tools (e.g. listservs, websites, national lobbying and fundraising initiatives and other forms of continued coordination and communication) as a first attempt was made to examine the

Every African grandmother at the Gathering came with a story of hardship, sorrow, courage and the determination to make life better for themselves, their orphaned grandchildren and their communities. Several of the grandmothers talked about how difficult it was to speak of their lives and losses and how it “opened old wounds.” During workshops, many broke down as they spoke of their lost children and their grandchildren, and those in their company wept with empathy and shared sorrow. And yet, nearly every workshop ended in joyous song, reflecting the triumph of the spirit, the hope that can be found within the depths of despair, and the strength in solidarity that the bereaved were forging with their sisters from Africa and from Canada.

We honour all of them, and share just a few of their stories here.
meaning of solidarity, and of building a movement of support in Canada. The Foundation was expected to continue its support by providing information about the Canadian groups that exist and what they are doing, as well as information about the African grandmothers and how the various projects support them on an ongoing basis.

Canadian grandmothers explored the range of skills and experience they brought as educators, medical and health experts, administrators, drummers, artists, community developers, counsellors, social workers, business women, international development workers and writers, and concluded that, together, they represented a wealth of expertise, energy and principles, and shared in common an understanding of the importance of relationships between grandmothers and grandchildren. They also shared a commitment to a diverse movement that would include grandmothers from a wide range of backgrounds, engage grandfathers, and work with young people to reinforce the connection between generations.

**COMMON GROUND**

Both sets of working groups discussed the fact that their particular kinds of wisdom, know-how and experience often are not perceived as ‘expertise’, although these are the life skills that contribute to working across differences and lead to mutual respect. They discussed the need for all societies to recognize and value the roles that older women play in their communities, even when encumbered by a scarcity of resources. Many grandmothers spoke of the importance of “head and heart working together.”

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**Laurance Mukamurangwa**

*Rwanda Women’s Network, Kigali, Rwanda*

Laurance tells us that she is a survivor of the 1994 Rwandan genocide, a widow, mother of six children and a grandmother of four. She lives at the Village of Hope, a group of 20 houses constructed by the Rwanda Women’s Network (RWN), in Kigali Urban Province in the country’s capital city.

“I am a grassroots woman who doesn’t know how to read or write but who is a very powerful member of the RWN, as a mobilizer and an activist. I came into contact with RWN when I joined the Polyclinic of Hope project in 1995 as a victim of rape during the 1994 genocide. I am HIV/AIDS-positive as a result of mass rape during the genocide and have been living positively for 11 years. I am the chairwoman of the home-based care group in my sector. It’s really a problem for us because we don’t have anything and must get food, clothes and school supplies, and you must remember that I am sick and I will die. The grandchildren are still young so you cannot tell them anything about the disease. But we tell them to love each other so that when the time comes and I can no longer be there, they will help each other.”

Laurance is 48, and nurtures as well as supports her four grandchildren, aged three months to five years, despite the hardship she has suffered. She told us that there are 20 grandmothers in her village looking after hundreds of orphaned children.
Several exercises were used to get to know one another. In some groups, members “interviewed” and introduced the women they were sitting beside; others brought a meaningful token into the discussion to help them begin talking about loss and grief; some facilitators encouraged group members to look carefully at one another and find similarities (for instance, the same glasses, the same caring expression, grey hair, gaps in her teeth that show when she smiles). The grandmothers explored what each woman present had in her heart, and found “love, self-awareness, song, a willingness to share problems with others, fear, hope and deep love for our grandchildren, the desire to comfort, the wisdom of generations, courage, plans for the future, trepidation about the future” and a reliance on song to communicate values and emotion. One group of Canadian grandmothers cheered one another for being “strong, rebellious and rowdy,” reflecting the unanimous and absolute certainty amongst all the grannies that as women, they are a powerful force.

Some unanticipated common ground was revealed. Aboriginal grandmothers from Nova Scotia, the We’koqma’q Qewiskwa’q Drum Group, described for the Africans the obscene chapter of recent Canadian history when First Nations children were forcibly removed from their homes and taken to Residential Schools. They explained that this experience robbed both their own generation and their children of healthy parents. Years later, as grandmothers, many of them are getting a second chance, becoming parents again as they step in to take care of grandchildren while their own children continue to battle the effects of this poisonous legacy. They talked about the universality of grief when loss is experienced by entire communities as well as at the individual level. The African grandmothers were stunned and moved by the stories of the Aboriginal grandmothers and the parallel hardship of their experiences.

There was a mutual recognition that worry about money is the number one priority amidst all the suffering, and that without lobbying for policy change, individual philanthropy could only go so far towards securing sustainable futures for orphaned grandchildren. African grannies spoke of their wish that they had access to their governments, and could hold them accountable for changing their circumstance. Because the demands of their daily lives already stretch them to the limit, the African grandmothers were thrilled by the Canadian grandmothers’ interest in lobbying internationally for change. And finally, the need for access to treatment and the desperate need for a cure for HIV/AIDS was in everyone’s mind. South African grandmothers gave it voice: “We need to shout to the whole world that they must try, by all means, to give treatment and a cure to each and every one who is positive.”
A preoccupation of all present was the question of how to channel funds and manage relationships after the Gathering. Many of the Canadian grandmothers expressed the desire to be connected in a deeper way to grandmothers in Africa, and felt that this was essential to inspire others to give and to continue the momentum and commitment that they felt after meeting the African grandmothers at the Gathering.

**ESTABLISHING CONNECTIONS**

There were some relationships which had already been established, prior to the Gathering, as a result of independent visits by more than one Canadian grandmothers’ group to Africa. The nature of those relationships and what was being learned from them was discussed in detail. At the end of the Gathering, the African grandmothers and project coordinators led a discussion on this ongoing theme, but since it was such a clear focus in the Canadian grandmothers’ initial Talking About Solidarity workshops, we will address it here.

African project coordinators and grandmothers discussed the problems around letter writing, earmarking funds for specific projects and ‘adopting’ groups and/or individual grandmothers, and suggested that these were not the most useful or tenable tools to maintain connections.

On the subject of earmarking, many of the African participants expressed deep concern, explaining that they were intensely aware of the overwhelming need of so many others — groups and grandmothers across all of Africa — and they were anxious not to benefit unduly simply because they were the groups and grannies fortunate enough to attend the Gathering in person. They talked about the democratic processes they had used to prepare, to represent their groups at home, and to participate in the Gathering: holding village meetings, discussion groups and engaging in a thoughtful selection process. They saw themselves as ‘delegates’ with the weighty responsibility of representing legions of grandmothers — both those they knew personally and the literally hundreds of thousands of grandmothers they would never meet across sub-Saharan Africa. In advance of the Gathering, they had convened meetings to exchange stories, craft messages, and choose the priorities to bring to the Gathering so that they could adequately represent the concerns of all. They felt fortunate not to have been among their peers who were prohibited from taking on this representative role by obstacles ranging from poor health, to overwhelming burdens of care, or because they had never been issued the birth certificate required to obtain a visa, or because they lacked the resources, information or access to translation to form or join a
Mary Anna Beer
York Region, Ontario

Mary Anna tells her story: “I fell in love with Africa upon first setting foot on the continent in 1993. At that time, I was introduced to many people in Zimbabwe, Namibia and South Africa. I knew I would return one day. In 1997 and 2002, I volunteered for Habitat for Humanity in Malawi and South Africa. In all three of those early trips, I was aware of and met many people living with HIV/AIDS. In 2003, I was chosen as one of four retired teachers to study the impact of HIV/AIDS on the education system in Tanzania, a trip sponsored by RTO (Retired Teachers of Ontario) and World Vision. On that mission, I learned a great deal about the impact of AIDS and began to see and meet older women who were caregivers.

In late 2003, a small group of inspired individuals started a committee in York Region. Our goals were to raise awareness of the AIDS pandemic in Africa throughout York Region and raise funds for the Stephen Lewis Foundation. A major success of the York Region Committee in Support of the Stephen Lewis Foundation was the involvement of the York Region District School Board (YRDSB). In 2004, the YRDSB sent a team of senior people to study the AIDS situation in South Africa and visit some of the projects supported by the SLF. I was also part of that trip.

Finally, in 2005, I traveled to Kenya where I worked in a facility for rescued street children near Nairobi and moved on to South Africa to work with orphaned and vulnerable grandmothers. Knowing that there were so many others, the delegates asked the grandmothers from Canada to trust the Foundation (or other organizations they support doing good work in addressing Africa’s AIDS pandemic) to know what was happening on the ground and where the need was greatest.

Several project coordinators rose to talk about letter writing and ‘twinning,’ about how good those had sounded to them when they first struck such relationships, but how onerous and challenging they had eventually proven to be. Many of the grandmothers could not write, and still others were dealing with too much in their daily lives to respond to all the correspondence they received. As a result, some of the grandmothers, whose circumstances allowed them to keep up communications, were benefiting from donations sent directly to them, while others were not, causing much unhappiness and discord in the groups. The project coordinators were also concerned about the disappointment that a lack of consistent and regular communication had caused for those on the other end of these relationships — and had decided with the individual grandmothers that accountability to donors was something which the projects were better able to manage than the individual beneficiaries.

The consensus amongst the African participants was that they deeply valued and appreciated the direct contact at the Gathering, and were eager to share the news of the commitment and love of the Canadian grannies with their sisters at home. But, they themselves acknowledged that they represented only a small part of the whole, and hoped that their representation would result in trusted donors in Canada continuing to fund an increasing number of groups supporting grandmothers across the continent.

The SLF was present for this discussion and heard both imperatives — the need to continue its support to more and more groups supporting grannies in Africa, and the need to ensure that Canadian grandmothers had a strong sense of what their money was doing on the ground and how it was helping in concrete ways. It was a challenging and intensely productive meeting.
Everyone agreed that it was important to share the stories and the messages from the Gathering with the world. Many expressed a desire to have a Grandmothers’ Day annually which could be celebrated across regions. There was a sense of urgency, in the desire of all, to sustain the momentum created by the Gathering and continue both the calls for and the flow of support to the African grandmothers. One grandmother expressed the sentiment of many — that this should be a wake-up call for leaders, politicians, activists and donors around the world.

Mary Anna Beer is a Special Advisor to the SLF for the Grandmothers to Grandmothers Campaign in Canada.
“I watched my daughter die every day for months, without soap to bathe her, all of us in one room, hearing her whimpers at night and wishing that I was the one who would perish so she could stay and raise her babies. The children were so afraid, but their mother would not let me tell them what was happening or that she would die. At her funeral they got so upset when they realized she was going to be put in the ground. I was too sad to help them.”
One workshop at the Gathering asked African and Canadian grandmothers the question, “What is grief?” Their answers:

Loss, **shock**, pain, **emptiness**, sadness, anger, loneliness, change, **depression**, self-blame, guilt, survivor guilt, fear, inertia, sorrow, **love**, denial, numbness, acting out, loss of meaning, disbelief, helplessness, loss of faith, broken heart

Many of the workshops at the Gathering addressed grief, and tried to capture the enormity of the loss to be dealt with by every grandmother who has been touched by the pandemic (those at the Gathering, and the hundreds of thousands in Africa they were there to ‘represent’). In these workshops, Canadian and African grandmothers shared their most profound experiences of personal loss and sadness. We felt the presence of so many deceased loved ones in the rooms where their names were invoked, in sadness, with intensity and love, as a backdrop to the discussions that unfolded around grief and how to cope with it.

In one workshop, participants were asked to take an object from a pile in the middle of the room and explain why they had chosen it and the loss it represented. The common experience of sadness in loss was apparent:

“I chose this red shoe because Nanny was a great dresser. Even in later years when she couldn’t speak, she always wanted to look great. Even with five years of ALS (Lou Gehrig’s disease) she never complained. Taking care of her husband and her children, I never had a chance to grieve.”

“My husband and I were together for 23 years. I am infected with AIDS, too. My second son doesn’t accept that his father gave me the infection. He doesn’t phone me or talk to me… Helping others gives me energy. It gives me life.”

“I picked this children’s puzzle for my sister…she died of AIDS…when I see this I think of her asking me to teach her children.”

“It’s been four months since my sister passed away. There isn’t a day I don’t think of her — there isn’t a day I don’t think of the Residential Schools and what it did to us.”

“I chose this jar of Vaseline because when my children were young, I used it after their baths…now with my grandchildren, I have come back to doing what I did with my children so many years ago.”

Workshop participants found that culture and geography do not distinguish experiences of loss and sorrow. But for the Canadian grandmothers, recalling their own
sorrows gave shocking context to the losses suffered by African grandmothers, losses multiplied by poverty, hunger, fear, stigma, illness, and the overwhelming burden of caring for so many dependent children and their own struggle to survive. One Canadian grandmother said of her personal loss that it was "the deepest pit of sorrow — but I don’t have to worry about sending my grandchildren to school in Canada. I can’t imagine it."

“Our systems of support in Africa have always been the family — they have been our safety net — but what do we do when our family of 25 becomes two through so many deaths?”

EXPERIENCES WITH GRIEF
This section records the part of the Gathering during which the African grandmothers explored their grief — compounded by hardship — and described the different ways they struggle to cope, and some of the strategies they have found most helpful.

Many grandmothers talked about the anger and frustration they felt as they tended to their dying children. They described feeling helpless as they watched their daughters and sons waste away — most often in agony, and without adequate medication, soap, salves or bedding. They told of their children’s children watching as their parents’ health deteriorated, and of the desperation of wanting to care for everyone and being unable to do so. The grandmothers spoke openly of the bewilderment, ignorance and denial surrounding AIDS, and the fact that their own knowledge of the disease had, in many cases, been vague or non-existent at the time, leaving them unaware of how to protect themselves during caregiving, and often fearful of the stigma and retribution that would come if anyone found out that AIDS had struck their homes. Many talked with great pain about children who had left home to seek work, only to return to die or be buried. “I watched my daughter die every day for months, without soap to bathe her, all of us in one room, hearing her whimperings at night and wishing I was the one who would perish so she could stay and raise her babies,” recalled one grandmother. “The children were so afraid, but their mother would not let me tell them what was happening or that she would die. At her funeral they got so upset when they realized she was going to be put in the ground. I was too sad to help them.”

“Our homes have become graveyards.”

Participants described how, in the throes of mourning, they suddenly had anywhere from two to 20 children to care for. We heard, again and again, about the hardship of losing a second child while still reeling from the first loss. The African grandmothers talked about the terrible loneliness, isolation, abandonment and grief they felt with the loss of each child. Each woman who spoke acknowledged — and others nodded in agreement — that they had never been able to grieve properly in the midst of everyone else’s sadness and confusion and the immediate needs of their grandchildren. All still felt overwhelmed by the responsibility for the material needs of their grandchildren, but also by the difficulty of dealing with the children’s losses on top of their own. Many of the grandmothers talked about the pain of having to share the burden of care amongst family and friends, so that their grandchildren lost first their parents and then their siblings as the community did what it could to cope.

“I have six children, inherited six orphans — their parents died, and I discovered I should have used gloves to care for them, and now I am sick — I had to accept that I’m positive. I have 19 children under my care, without the shoes, clothing or shelter I need for them.”

Worry about how to subsist was also a constant theme among the grandmothers, many of whom are poor enough that
ensuring adequate food, clothing and shelter for their families are daily challenges. Some said they felt that their grief would never abate, partly because of the extent of the death and infection all around them.

Several participants revealed ongoing disbelief at the turn their lives had taken:

“At 53 I can’t prepare my own destiny, I can’t rest and I can’t die. There are too many demands; many more are dying, bringing more and more children…”

“We are nearing the end of our journey…we need help because in the back of our minds, we know that we will die, and some of the children have HIV and will die — how do we cope?”

“I had 15 brothers and sisters. Now there are only four left. All [the rest] of them are dead from AIDS. I had ten children of my own and have lost eight. I care for all of the orphans in a four-room house, and they are walking almost naked. There is never enough food.”

“I am so tired, it is difficult to feed the children and take care of them the way their mother did.”

“I look young, but I am ill — I cannot work, my [CD4] counts are low, and I cannot get aid because I am only 53 years old. I have a two-room house, without adequate food, shelter, clothing for the kids — it is very, very painful.”

“I too, as I sit here in front of you am HIV-positive. My youngest grandchild is also HIV-positive. My biggest concern and worry are the living and sleeping conditions in my home. The children don’t own any beds. The few blankets that they have are ripped. They also don’t have much to wear. They wear ripped clothes because they have nothing else. And then our house collapsed on one side during the last rains. We only have two rooms left.”

Grieving orphans

Many workshops addressed a pressing concern for the grandmothers in dealing with grieving grandchildren, and learning how to provide the support they need to heal and eventually lead happy and fulfilling lives.

We heard from grandmothers who were confused but desperate to understand their grandchildren’s behaviour and grief in order to better support them. Projects working with children orphaned by AIDS were strongly represented at the Gathering; the Foundation recognized the necessity of involving the grandmother-caregivers in the children’s healing processes.

The grandmothers and project coordinators held intense workshops to explore this worrisome issue.

Participants discussed obstacles to their healing, beginning with denial — first by the dying (overwhelmingly it was a daughter whose husband or partner had long since died or left), and also by the grandmothers themselves. They described their denial as being motivated by fear of reprisals (if community members found out), by shame, and by an unrealistic hope that if they refused to acknowledge the inevitability of their children’s death, their grandchildren would somehow be spared the agony. As one grandmother put it, “In our culture there is a lot of denial. Our pain is so great we do not want to put the children through it. We think if we don’t talk about it, it will be easier for them.”

Workshop leaders explained that while avoiding the topic of illness or death is common, even when grandchildren raise the topic, it can be very damaging, suggesting to the child that she or he should repress feelings and pretend that nothing is happening. It might also cause the child to feel responsible for taking care of the grandmother.

There was consensus amongst participants that breaking the silence is critical for bewildered and frightened children to understand what is happening and begin to deal with it. Grandmothers exhorted one another to tell the truth; to repeat the facts of what is happening clearly and openly and to admit when there are unknowns; to keep the child physically close and comforted; to be as supportive and predictable as possible; to show emotions and be a role model for the child so that he or she will also feel entitled to grief and (cont’d on p.28)
“I started attending the Gogos’ support group in 2002 whereby the group helped me to deal with the loss of my two children with support I got from other grannies. While I was attending the group, I realized I was not alone thinking that raising orphans is hard, especially when you’re as old as I am. I have to help [my granddaughter] to cope with the loss of her mother. In 2003, I had a stroke and I lost my job, but still I continued to attend the support group because of its importance.”

At times it seemed that the grandmothers were at a loss to describe how the devastation of their loss was multiplied many times over by the fact that they and their grandchildren lack the basics of mere survival: food, clothing, shelter and education. But there were other hardships touched upon as well — subjects that could have been the topics of entire workshops in themselves:

**LAND RIGHTS:** We heard that the lack of inheritance rights for women put grandmothers in terrible jeopardy. The stigma around HIV/AIDS often meant that, although grandmothers may have been staying in a relative’s home and caring for the orphaned children left behind (their daughter’s, son-in-law’s, sister’s, etc.), it was not uncommon for a male family member to swoop in and take possession of the land and the dwelling. In some instances, the grandmother was defined legally as a squatter without any rights, and could be jailed for staying in the home to care for her grandchildren.

**ELDER ABUSE:** We heard shocking stories of abuse of older women by angry community and family members because of their relationship to the person who died of AIDS. We also heard of angry, uncontrollable older orphaned children who — furious at the world and at the loss of their parents, and unable to get the help they needed — were sometimes verbally or even physically abusive to their grandmothers. We also heard of an alarming increase, in some areas, in the sexual assault of older women by men who, it is said, erroneously believed that all older women are free from infection.

**PARENTING:** Participants became keenly aware that Africa’s grandmothers are parenting in a situation that has no parallels and therefore no models. Only the exchange of experiences with other grandmothers and experienced counselors can assist these caregivers as they learn to observe their grandchildren more closely, learn how to interpret behaviour, and help the children understand what has transpired and move on from their losses. One grandmother recounted, with bewilderment, that her granddaughter had asked to leave a mirror at her mother’s graveside so that when she emerged from the grave, she would see her daughter’s face. The grandmother was at a loss about how to interpret this sad request and comfort her granddaughter.
anger. The grandmothers talked about anticipating different reactions from the children as they were being told of their mothers’ status or, indeed, of their own. We heard that it is quite common for a child to appear not to be listening, as this is one way of coping with the pain. We also heard that the children may ask the same questions over and over again, and fill in details that they don’t know. Since imagined details are usually distorted and inaccurate, and can sometimes be more horrifying than the actual details, such misperceptions can interfere with the healing process.

There was discussion of the fact that a child may feel terrible guilt because he or she is still alive. We heard stories of children who only understood that their mothers or fathers had died when they attended the funeral or were later taken to the graveside.

The grandmothers who related their experiences found this set of workshops especially painful. They proved very difficult, as well, for the Canadian grandmothers who listened but everyone found them cathartic, sharing tears along with much singing and comforting.

It doesn’t help, we heard, that orphans can often behave in terribly challenging ways – acting out physically and emotionally, running away, becoming withdrawn, having nightmares, or railing against their grandmothers. Grandmothers discussed their struggles to cope, and to provide love, and participants heard about the importance of creating environments that allow bereaved children to talk about their pain. Project coordinators talked about the need to have orphaned children tested. Although the majority are not HIV-positive, those who are will have special needs, including heightened attention to nutrition and antiretrovirals (ARVs) and other medications introduced at the appropriate times.

Some grandmothers spoke of their fear about losing their homes. Others were anxious about being able to keep their grandchildren in school, still others were afraid of losing them to AIDS, and some spoke with dread of losing children to the streets and to the ‘survival sex’ that too many impoverished, hungry and hopeless youth succumb to as a last resort. The projects, working with orphaned children, described how they tried to help grandmothers with the ongoing challenge of talking to their grandchildren, and tried to allay the fears felt by both generations.

DEPRESSION: The depths of despair had provoked suicidal thoughts among many, and the grandmothers who spoke of their depression also described the hope and succour they receive by linking up with projects that bring them together with other grandmothers and provide them with emotional and financial support.

SEXUALITY: In several boisterous exchanges, grandmothers from Africa talked about their fears around sex and sexuality. Some said how difficult it had been to educate themselves about HIV and AIDS and discuss such issues with their grandchildren — but they had done so to stop the cycle of infection and death. For the grandmothers themselves, we heard that the fear of contracting the virus put a strain on their sexual relationships with their spouses, and for some, the combination of a lack of power to say no to unprotected or unwanted sex, and cultural norms that make it difficult to raise the subject of condoms with their husbands, leave them in a constant state of worry.

HIV+ GRANDMOTHERS: There was ample evidence of a lack of targeted assistance and counselling for HIV-positive grandmothers everywhere. Many of the grandmothers are in remote areas, caring for many children, and have neither the money nor the time to visit far-away clinics. Many told stories of contracting the virus while tending to their dying children, unaware of the precautions required. The grandmothers, who are HIV-positive, have the added burden of being constantly tired and sick as they push themselves beyond what they can manage physically to care for the children. Several project coordinators expressed concern that because so many grandmother-headed households were without adequate food, many grandmothers were starving themselves in order to feed the children on a regular basis. This caused the coordinators
particular alarm when the grandmother was HIV-positive and the need for good nutrition was even more urgent.

DIGNITY IN DEATH: A great many grandmothers spoke of the emotional devastation they felt because they lacked the money to pay for funerals or proper burial ceremonies and graves for their daughters and sons. They spoke of the stress and sadness it caused them, as they nursed their children to their graves, to know that they would not be able to avail them of dignity in death. One grandmother told of a "sea of graves" in her front yard and her guilt because there had been no proper burials, no religious figures and no flowers at the funerals of her family members.

Each personal account of loss and continued deprivation made one thing abundantly clear to all present: there is nowhere near the support to meet even these grandmothers’ needs, let alone the countless additional caregivers who need help. Many project coordinators said that they were only just beginning to reach more of the grandmothers through their home-based care programmes, orphan-care programmes, etc., and to realize how much, much more was needed. Grandmothers in remote and rural areas, they said, are particularly isolated.

STRATEGIES FOR COPING: PROGRAMMES THAT OFFER HOPE IN HARDSHIP
African grandmothers were unanimous in their conviction that group support, counselling, and a space to cry, talk, laugh, dance and sing with other caregivers are absolutely essential for coping with the burdens and the devastation of HIV/AIDS. They expressed the unqualified belief that projects which provide emotional and, sometimes financial support, are sustaining and fortifying them.

Several strategies and advice were common among the grassroots projects:

- Help grannies identify the pain of loss due to HIV/AIDS;
- Help grannies appreciate the usefulness of grief counselling, and acquire the skills to help and support one another, since unexpressed grief does not go away, but manifests itself as physical and emotional difficulties;
- Facilitate meeting with other grandmothers who are talking about challenges, grief and grandchildren, as these encounters alleviate loneliness, and can often help when dealing with difficult situations;
- Provide support and relief for grandmothers through moments of laughter, enjoyment, and respite;
- Create a safe space to talk about the difficult work of caring for sad, angry and bewildered children, in order to discuss the challenges they present without fear of stigma, judgement or recrimination;
- Offer grandmothers who have given up hope, or who are feeling overwhelmed by their circumstances, a forum in
which they can develop skills as community leaders, have their courage and resilience recognized by others, and find avenues to self-esteem and healing;

• Provide a venue in which groups of grandmothers can discuss and educate themselves about land rights, elder abuse, HIV/AIDS transmission and prevention, parenting skills, nutrition, access to pensions and other topics;

• Allow for advocacy to support grass-roots organizations, but also to gain financial help and skills training for caregivers from governments, in addition to education for children at no cost.

As one grandmother who runs a non-governmental organization (NGO) working with widows, grandmothers and orphans remarked, “You don’t sow seeds of hope if you cannot justify that hope.”

GRANDMOTHERS GALVANIZING: LOOKING BEYOND GRIEF AND INTO THE FUTURE
Grief, poverty, hunger, vulnerability and fear about the future dominated discussions at the Gathering. And yet, by the time they left, both Canadian and African grandmothers spoke with exaltation about the joy, hope and inspiration they felt.

For the African grandmothers, despair was initially supplanted by hope and purpose when they formed or joined their own groups; the Gathering added to that solidarity, organizing a much wider circle of support, a chance to unburden themselves and a commitment to improve the quality of their lives, however modestly.

There were projects that first tapped this supportive resource within caregivers — whether the groups were founded by grandmothers, or the grandmothers found one another through other community AIDS efforts such as orphan care, home-based care or organizations of people living with HIV and AIDS. Each group has given its grandmothers emotional and material support, hope for the future and the sense of empowerment that comes from having one’s voice heard.

Many of the project coordinators, who attended with the grandmothers (many of whom are grandmothers themselves), talked about an increasing awareness

GRANNIES’ STORIES

Karmela Kasule
Reach Out Mbuya, Kampala, Uganda

Karmela speaks: “I am an HIV-positive grandmother living in one of the communities designated to accommodate people displaced by war in northern Uganda. I am taking care of over 28 dependants. I do beadwork and work in a stone quarry.”

Karmela is 51, and cares for a family made up predominantly of orphaned children, who range from infants to young adults. Karmela raised five children, three of whom have died of AIDS. “I prayed that God would take me instead of my children,” she says. The sorrow of watching the lives of her children snatched away and the memory of throwing dirt on their caskets still causes Karmela to fall silent. She says that she has not had time to properly mourn her losses. More relatives died in recent years — her sister, her brother — and there were too many children who needed her care. “They have no parents and nowhere to go, and they are my family. I used to think to myself that I was being punished by God when new children were brought to my household. But even though I had no money or room for them, I would have never considered turning them away.” Her tiny house has no electricity or water and the children sleep in rows. “I managed to rent an extra room with our neighbour to add a little more space to our two-room house, but the children still have to sleep on the floor.”

Karmela has pinned her hopes on the children’s education. Her husband of 35 years sleeps outside the house to make room for the many smaller children, the youngest of whom is three months old.
of the need to include grandmothers in all their ‘formal’ HIV/AIDS activities. We learned that a lot of these projects had not started off with a focus on grandmothers. But, they soon realized either that such groups were needed or that they were forming spontaneously, and that grandmothers formed the sustainable centres of community care. Many community groups dealing with orphaned children have come to realize that children cannot flourish — even with their assistance — if a grandmother is at home, unwell emotionally and desperately impoverished, because the children are likely to stay home to help her manage.

Naturally, projects established to work with grandmothers had much to share about their successes, and what they had learned in the course of their work. But, in every instance, the relationship grandmothers forged with one another under the auspices of grassroots projects in their communities had lifted them out of despair, helped them to deal with their grief and depression, and given them the strength to cope with their difficult lives.

Common themes emerged about what is truly helpful for the African grandmothers in their communities — primarily self-sufficiency and independence.

We heard that one-time handouts are not the answer. Grandmothers said they would much prefer to be trained in practical ways so that they could support themselves. Some had begun to do so, making and selling crafts, creating community gardens, and engaging in other money-making activities. Those organized to earn money in groups appreciated being able to rely on others in times of difficulty. It was acknowledged that no one model was universally successful — different cultural norms and circumstances (rural groups vs. urban, for instance, or countries where drought makes planting impossible) would necessitate different models.

The importance of connections resonated with the Canadian grandmothers, who agreed that they play an essential role in building self-esteem, a sense of purpose and appreciation for the skills they contribute in their communities. All participants spoke with a feeling of ‘empowerment’, self-determination and Common themes emerged about what is truly helpful for the African grandmothers in their communities — primarily self-sufficiency and independence.

Karmela dreams that when the children grow up, they will be able to get jobs and help the younger ones get through school. She realizes that it is a tenuous hope, however, because in Uganda, the cost of school fees, uniforms and supplies are prohibitive. Grandson Jimmy is now eligible for university, and dreams of being a lawyer, but paying tuition is out of the question. As it is, Karmela struggles to find the money to send her five youngest school-age children to primary school. “I can’t afford the school fees, so they must stay at home every day.”

Karmela works at a stone quarry together with hundreds of other residents from her area. She goes to work every morning and returns at night, after spending hours in the burning sun in a cloud of red dust, her hands torn up from the work of hammering large rocks into smaller pieces. The work at the quarry provides the family with the equivalent of US $11 every two weeks. A 50kg bag of maize meal, the amount she needs to feed her family porridge for two weeks, costs $24. When the older children are not in school, they come to the quarry to increase the family’s yield of crushed stone. “I know it is bad for my health, but what can I do? I have to bring food to my children, even if I know this work can worsen my condition.”

Karmela feels sure that she contracted HIV while nursing her late son through the worst of his illness. “He had so many wounds. I would come home from the quarry with wounds on my hands and tend to his wounds. I wasn’t aware that HIV is transmitted through such contact.”

Like the other grandmothers, Karmela worries about what will happen to the children after she dies. “Who will take care of them if I fall sick, and make sure they are not orphans again?” Fortunately, her husband has tested negative, and Karmela tells us they are extremely careful to avoid transmission. “I am grateful he can take care of me should I fall sick.”
independence. Project coordinators and grandmothers alike talked about the importance of listening as grandmothers identify their own needs, and of involving the grandmothers in decisions taken to assist them. Several grandmothers raised the issue of empowerment through political involvement at the community and national levels, whether advocating for pensions, inheritance rights, respect for their wisdom, recognition of the roles they play in their communities and societies, legislation benefiting and protecting older persons, access to government grants or working to end the stigma around HIV/AIDS.

Finally, several grandmothers talked about the peace of mind they experienced working with projects to create memory books with their dying children, or to write their own wills. These preparations for death have helped them manage some of the inevitable loss their grandchildren experience, by preserving loving memories of the deceased, and allowing grandmothers to leave something behind for their grandchildren.

Here are just a few examples of the many activities we heard described that have given the African grannies support and pride:

- Grandmothers with the Kenya Widows and Orphans Support Programme (KWOSP) have come together to sew school uniforms for orphans, do beadwork for sale, and have taken up mechanics’ vocational training and dressmaking;

- Grandmothers affiliated with CINDI (Children in Distress) in Zambia have helped mobilize their communities to offer support for orphans and provide care to child-headed households;

- The Busy Bees cooperative, a grandmothers’ group affiliated with PALS in Zambia, has become self-sustaining by making and selling crafts and school uniforms. They prepare food for sale, and are now working on a vegetable garden to feed orphaned children. [This group talked about its need for sewing machines at the Gathering, and has since received funding from the SLF for additional machines from funds sent in by Canadian grandmothers groups.];

- The Gogo Grannies from South Africa,

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**Zodwa Hilda Ndlovu**

Treatment Action Campaign (TAC), Durban, South Africa

Zodwa speaks, “I will die one day; maybe next year, my CD4 counts will go down [an indication that the immune system is failing]. But I know what I will have died of, and I know that I am using my time right now to do what I can. I lost everything.” She draws her eyes tightly shut. “We are going forward, we are going to fight the stigma, we are going to fight the discrimination, we are going to fight the virus itself. I tell people I am HIV+ and there is life on the other side for the people who are positive. Even if you are positive, come out from the shed so you can get help!”

Of her work at TAC, Zodwa told the group, “The organization does give me power, and it does give me strength to be an activist. It also gives me power to know that when I lost all my kids, [I wasn’t alone].”

Zodwa’s daughter gave birth to an HIV-positive baby before realizing that she herself was infected. Zodwa, who was then 55 years old, and her husband decided to care for their granddaughter to allow their daughter to continue her education. When the granddaughter was still quite small, the daughter fell ill. A trained nurse, Zodwa travelled back and forth to care for her daughter. The journeys took a toll on Zodwa and forced her eventually to resign her paid nursing position. Her daughter passed away, and Zodwa learned that she, too, had contracted HIV. At the time, ways to prevent transmission
said that although for the first three months, their meetings were “just sitting there crying, going to funerals, and singing.” Since then, activities for grandmothers have expanded;

• At Cotlands, “we do singing and praying. We do our jobs — some do sewing and some make necklaces — they give us food, and we talk — just talk, laugh and be nice.”

COMMUNITY OF SUPPORT
The African grandmothers talked about the power of group discussion and bereavement counselling in many workshops. Having a forum gave them a voice in which to discuss their problems, feelings and needs — and an active role in problem-solving for themselves and for their peers. This helps to ameliorate their sense of helplessness, and many of the grandmothers talked about moving from solitude and a feeling of powerlessness to becoming community leaders and healers.

weren’t well understood, particularly in rural areas.

Shortly afterwards, Zodwa’s only remaining child discovered that he was HIV-positive. Upon learning this, he doused himself with gasoline and set himself alight. He died instantly.

His suicide note revealed that he did not want his mother to re-live witnessing the agonizing death that his sister had endured. He didn’t realize that Zodwa was also HIV-positive.

The granddaughter’s paternal grandmother made a claim to take the granddaughter away, citing customary law that grants the father’s family the right to retain custody of orphaned children. Zodwa agreed to give up the child because she was fearful of leaving the child without a caregiver after her own death.

Zodwa began referring to herself as a mother in the past tense, “I was a mother.” With her family gone, she turned her efforts to supporting other orphaned grandchildren in her neighbourhood in Durban, South Africa. Each morning, she runs a small soup kitchen for orphaned children to visit on their way to school. Often the children will return at other meal times, asking for food and seeking company. In this way, she sustains a small legion of children who see her as their grandmother. “They call me Mama Darling, because I tell them they are all my darlings,” she laughs.

Zodwa is a TAC volunteer; she conducts training sessions in the community, looks after sick people and is a founder of a support group. “I am not the only mother that is positive, there are other mothers that are positive hiding out there…I must try and do something for them,” she says.

Zodwa tells the story of how she learned of her HIV-positive status: “The reason that made me go for testing…I was not sick, I am a community worker…and I started a group of home-based care workers [volunteers who look after sick people]. I went because I wanted to tell the truth (cont’d on page 34)
The isolation, loneliness and feeling of abandonment by society was immobilizing for the grannies, in every instance, and even dangerous to their health. Many had felt suicidal or depressed and unable to function until they joined a group of other grannies and were able to talk, comfort others and receive help themselves.

One woman said that when she lost her daughter, she wanted to die, and then she was invited to a social gathering to make crafts. “What is the connection between my broken heart and making crafts? While making the crafts, they talk and talk and talk, and they are not alone.” GAPA’s project coordinator added that when the isolation is broken, the despair begins to be more manageable.

Breaking the silence about HIV/AIDS in the grandmothers’ groups is a powerful starting point for healing. One project coordinator put it this way: “HIV can be turned down. We have turned the face of HIV sadness to smiles in the community because we, as the community, picked up and went and started helping our brothers and sisters...we have seen a change in the face of HIV and the stigma.”

Another says, “I have sisters here...I can cope with everything now. I feel strong about everything. Before I was feeling that I could also die. I was asking every year, why me? My heart was opened when [my granny support group] opened. I would have died long ago.”

And still another says, “As grandmothers, we decided to start something instead of just asking from people...we try to sell the stuff that we knit and the money that we get, we use it to help ourselves, and we use it to help each other. We do home visitation amongst ourselves, and if one of us doesn’t have anything, we help that person to get food.”

LACK OF TIME
Repeatedly, we heard about the lack of time for grandmothers — to grieve, to reflect, to invest in training and income generation — all the while caring for dying children and orphaned grandchildren. GAPA started a preschool programme in order to afford the grannies in their groups more time to work and network.

Grannies’ Stories (cont’d from page 33)

[about her children’s deaths] to the people. I did not think that I would be positive. I was just telling people [the home-based care volunteers] that if you are going to the community you must talk to them and tell the community that you know your status. If you are free from the virus, you must learn to stay free. Don’t ever become positive. Stay negative. So I went to the clinic...when I get there, I know the people that are working [there], some of the nurses I worked with and the small girl that is a counsellor. She knows me because I used to come to the same clinic to educate the patients. She asked, ‘Ma’am, you want to be tested?’ I said, ‘Yes, how can I not be? Because I am a community worker. I don’t want to tell lies to people.’ She did a little bit of pre-counselling and then I went for testing and I was supposed to come for post-counselling. When I came for post-counselling, she looked at me...I also looked at her. She said, ‘I’m sorry.’ I said, ‘Why are you sorry?’ ‘I’m sorry ma’am, you are HIV-positive.’ I said, ‘What!? How can that be?’ Just imagine, a person who is a community worker...a person who is an activist, an HIV-activist...being told she is HIV-positive. I say, ‘Why? How did it happen?’ And the counsellor said to me, ‘I don’t know how to do the post-counselling with you, Ma’am, because you are the person who is doing that job for other people.’ She gave me my results and I took them and put them in my bag. I went home but the first question that came into my mind was, ‘What is my husband going to say? how am I going to tell my husband this thing? how did it happen?’ I went home. I did not tell my husband. I stayed for two months not telling that I had such a thing. after two months, I went to another clinic because it came to my mind that I am supposed to go back to the clinic after two months. I went to the other
We also heard that grandmothers, caring for many children and trying to eke out a living, did not have the luxury of ‘quality time’ with individual grandchildren, or even enough one-on-one time to get to know much about them. The grandmothers were pained by this lack of time and felt it as a real hardship, knowing that the children in their care are enduring extreme hardship and could benefit so much from more emotional support and individual attention.

We have cited just a few examples of the activities that groups undertake in their work with grandmothers. At the end of this report, there is a listing of all the groups that attended and what they do. For each group that attended, there are yet hundreds more across the continent of Africa who are providing vital life-sustaining support to grandmothers and the orphans in their care. The work continues.

Story compiled with notes from Gillian Hewitt.
“One woman felt that she ‘was finished’ when she learned that her daughter was HIV-positive. When her family found out, they did not want to share household items such as dishes, sheets or soap with her. Group discussions unleashed an avalanche of similarly painful anecdotes about the stigma associated with death from AIDS.”
A number of workshops addressed the stigma that still surrounds HIV/AIDS, and the ways that discrimination, behaviour and poverty compound its effects.

Prior to the Gathering, many of the African grandmothers requested a workshop to provide an overview of the impact of AIDS in Africa. This was facilitated by Dr. Alan Whiteside from the University of KwaZulu-Natal in South Africa.

We heard from Alan that the world is still learning about the AIDS pandemic and its many complexities as a disease — and as a force affecting sub-Saharan Africa specifically. What we know for sure is that the pandemic will get worse before it gets noticeably better, because the death toll has yet to reach its peak. Just a sampling of the devastating statistics he quoted:

- In Kenya, 1.5 million people have died of AIDS to date, and 1.5 million orphans carry the virus; mortality rates are steadily growing, and by 2010 there will be an estimated 1.9 million orphans in Kenya alone;
- In Swaziland, there is now only a 28% chance that a 15-year old boy will live to age 50, and a 22% chance that a girl will live that long. Prior to the epidemic, the likelihood was 92% for boys and 97% for girls.
- In some countries, 25% of children will be orphaned children. “The number of orphans carrying the AIDS virus is a ticking time bomb,” Alan told us.
- In South Africa, a woman between 25 and 35 years old is 3.5 times more likely to die during those years than those of comparable age in 1985. This statistic struck an especially familiar chord for the African grandmothers, who discussed the unprecedented phenomenon of a middle generation being wiped out, leaving children and grandparents or no caregivers at all.

Many of the African grandmothers talked of the shame and stigma that entered their lives along with the disease. One woman felt that she “was finished” when she learned that her daughter was HIV-positive. When her family found out, they did not want to share household items such as dishes, sheets or soap with her. Group discussions unleashed an
avalanche of similarly painful anecdotes about the stigma associated with death from AIDS.

“A child, after losing her parents to HIV, she too [may be] HIV-positive. It is very difficult and often grannies do not tell the child because of the stigma she will receive at school.”

A Kenyan grandmother told us there is often a kind of ‘veil’ blocking communication between grandchild and grandmother. The child knows something is wrong, and the grandmother knows the child’s status is positive, but neither can bring themselves to disclose their terrible knowledge to the other.

A South African grandmother of an HIV-positive 10-year-old girl feared that if the child knew her status, she would let it slip and then experience stigma, or she might become convinced that she would die as her mother had. When she finally told the child, the girl revealed that not only had she known (or suspected) for some time, but she had not shared her suspicions because she wanted to spare her grandmother the burden of sadness and worry.

The fear of stigma is not without grounds. Often the result of a positive diagnosis is abandonment followed by isolation and solitary grief. Many of the African grandmothers had stories to tell about family members who had kept their status secret from others — spouses, parents, children, grandmothers — either because of the fear of reprisal, or out of shame, or both.

Grandmothers’ groups at the Gathering shared their strategies for bringing reluctant new members into their groups, often by inviting them to social or informational events where AIDS is not explicitly mentioned and stigma can be avoided. Other groups were struggling with the need to break through the stigma by being transparent and open about their HIV/AIDS focus, while at the same time wanting to protect the privacy, safety and accessibility of the people who attend their programmes and clinics. In the words of researcher Alan Whiteside, “In Africa, studies show that HIV/AIDS increases poverty. We are expecting the poor to care for the destitute.” The burden of caring and paying for ill family members, and the loss of young income-earning people, is economically disastrous for households that have always lived in, or on the brink of, absolute poverty. Alongside parents, the loss of teachers, health professionals, civil servants — an entire young adult and middle-aged generation — has placed untenable strains on African health systems and economies, causing families, cultures and societies to unravel.

Throughout the workshops, grandmothers discussed some key factors contributing to the spread of HIV and the continued silence and stigma in so many communities:

A long period of denial by politicians, in tandem with an international community that provided too little and too late, has translated into millions of unnecessary deaths. Access to adequate health care, proper nutrition, medications for opportunistic infections, and AIDS treatment, is woefully inadequate across the spectrum of those infected, and even more egregiously absent for impoverished grandmothers and children.

Stigma and the taboos that surround inter-generational discussions of sex, sexuality and sexually transmitted diseases, in almost all cultures in the world, feed a cycle of ignorance and transmission — and interfere with the effectiveness and pervasiveness of prevention programmes. There has been a marked improvement in these areas over the last few years, but much more must be done to make future generations safe.

Underlying the pandemic is the low social status of women. Gender inequality, on every front, creates a breeding ground for HIV. Women who are unable to realize their sexual rights — to end cultural acceptance of polygamy, female genital mutilation, early marriage and forced pregnancy — are naturally at risk.
Without autonomy, economic independence or political power, women remain desperately vulnerable. Marital rape is not acknowledged as a possibility in most countries, and weak legislation and enforcement make women targets for intimate partner violence and rape. “If we continue to allow cultures to go on as they are, that is, as long as women have to sleep with men without being able to talk about AIDS, the prevalence will remain high,” said one African grandmother angrily.

Religious leadership was cited, by many of the grandmothers, as an obstacle. An indignant African grandmother told us that “the religious leaders are often shaming and blaming rather than using their power in the pulpit effectively.” Another told us, that in her experience, churches mislead people by saying that their faith will be enough to protect them.

From a number of workshops, we heard that the combination of stigma, religion, fear and blame creates a powerful force impeding effective work on AIDS. A Rwandan grandmother described how sexual domination of women led to the use of rape as a weapon of war during the 1994 genocide in her country. Mothers, daughters and children tested positive for HIV as a result of sexual assaults suffered during the 100-day massacre. “The guards would separate the men from the women, and then again the women from their daughters, and would rape again and again. It is very difficult to talk to the children and women about the infection,” she said, “because of the horrible indignity of the rape itself.”

**HOPE FOR THE FUTURE**
Prevention was discussed, particularly in the contexts of caring for the dying, and worrying about raising children together, when some are HIV-positive and others are not. Alan stressed that without prevention, all attempts to deal with this epidemic will be futile. Treating the sick with ARVs, without also preventing more people from becoming infected, he said, “is like leaving the tap running and just mopping the floor.”

Many of the grandmothers discussed working through their projects to raise awareness of how the virus is transmitted, to debunk myths, and to promote safer sex. Everyone was hopeful that treatment and care would break the back of the pandemic, and at the same time, there was an overwhelming awareness that drugs were not widely available and were still often prohibitively expensive. Alan gave an example of this, “The aver-

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**Grannies’ Stories**

**Maria Virgilio**
Kukumbi – Organization for Rural Development, Kukumbi, Mozambique

Maria speaks: “I have 14 children who are orphans. I am a member of a grandmother group supporting other vulnerable children in the community. I depend on agriculture: vegetables, cassava. This is how I survive. In my community there are so many other grandmothers who are not receiving any assistance.”

Ten of the children in her care have been orphaned, and four have a mother who is too ill to take care of them, so Maria has stepped in. She herself had eight children, four of whom died of AIDS.

Maria’s small grandmothers’ group has a little land where they grow vegetables to sell. Some of the proceeds are saved for the group and the rest of the funds go to the needs of the children.

“The money is not enough; some days we don’t have lunch or dinner, and the children go to sleep without eating anything. There is not enough for school uniforms.”

Maria gets up early every morning to go to the market to sell vegetables and when she returns, she prepares lunch for the children, if there is food. Some of the children can go to school, but she has difficulty affording the mandatory uniforms. When those who go to school return home, Maria prepares dinner. She told us that she receives two dollars a month from her community to support her. The space she lives in is not big enough, so some of the children sleep on the floor.
The estimated cost of treatment — at the lowest price available — is $150 per person for one year. That is for the drugs alone. We all know that it takes more than drugs: laboratory tests, ancillary work, doctors and infrastructure.”

He also underscored that it is critical to increase the understanding of the importance of a healthy lifestyle and diet for people living with HIV, along with making care and drugs universally affordable and accessible.

There was consensus amongst all the grandmothers and project coordinators that keeping children in school was essential. For children who are not infected, the longer they stay in school, the less likely they are to become HIV-positive, since education, empowerment and awareness are strong elements of prevention. The grandmothers felt that educators needed to be made more intensely aware of all the issues surrounding the virus, since schools are, after all, community centres for children and youth.

Canadian grandmothers spoke about their current and future roles in beating the AIDS pandemic. They discussed lobbying governments to fulfill their obligations by providing support to African countries. They understood that international pressure plays an important role, not only by affecting the levels of assistance that flow to Africa, but also by influencing the responses of African governments. The world needs to send a loud and clear message that the situation is intolerable; what is being done is negligible given the cost in human lives.

The African grandmothers confirmed that every grassroots initiative with which they are involved knows what needs to be done, can rely upon legions of volunteers from the community, and has innovative and effective strategies. But their reach is simply not long enough because the lack of funding lessens their impact at every turn. Whether it’s school fees, money for food, shelter, awareness-raising and treatment literacy campaigns, orphan care, home-based care, support and bereavement groups, or voluntary counselling and testing and provision of treatment, the money available is nowhere near what is needed.

They were intensely hopeful that the Gathering would raise awareness and inspire people to give, and to recognize the expertise of Africans themselves (and particularly the grandmothers) in dealing with the pandemic in their communities.

**Akidi Balbina Okot**  
TII KI KOMI Women’s Group, Gulu, Uganda

Akidi says, “I am Akidi Babina Okot, aged 64, from northern Uganda. I have 10 children. Four have died and left me with 13 grandchildren. My husband is alive, but cannot walk as he was hit by a speeding vehicle last year. I earn my living as a peasant farmer growing food crops, part of which I keep for food (it’s never enough) and part of which I sell for fees. Every morning I wake up, and with a hoe on my shoulder go to the garden to dig up to mid-day. After digging, I have to pick up some greens from the garden to make sausages and then some firewood which is carried on the head. On reaching home, I go back to collect water for cooking. The greatest challenges are food, paying school fees, clothing, bedding, medical treatment and transport.”

**Margaret (Maggie) Njobvu**  
Children in Distress (CINDI), Kitwe, Zambia

Margaret speaks: “I am 61 years old with seven children. Six of them have passed away. Ten grandchildren are in my care; two of them are HIV-positive and quite ill. Two of my own children are also critically ill. I started suffering in 1999; I am a woman who knew nothing about HIV/AIDS. My husband became sick with TB and in 2000, I became sick with TB. After eight months of TB treatment, I became sick again. I found out then that I was HIV-positive. My husband was a truck driver and had been sick for a long time. He was taking medication for a number of years, but he did not tell me of his illness. He said he didn’t tell me because he thought I would divorce him, though he had deserted the home for six months to be with another woman. In 2000, I started taking ARVs.”
“In North America, we are notorious for ‘Me, Mine, and More’ and we have got to be ‘Ours, Us and Enough.’ If I were to make a wish for any child, it would be ‘Enough’ – enough love, enough food, enough medicine, enough uniforms for school.”
Profound and pivotal conversations took place at the session focusing on orphaned grandchildren and other vulnerable children. The African grandmothers brought us sad and painful information, but at the same time showed remarkable insight and thoughtfulness. Their resilience shone through every discussion, and demonstrated vividly why there is still so much hope for these children.

From Canadian grandmothers, we heard repeated expressions of concern, compassion, and empathy. Together, we were struck by the echoing sentiments of African women with little or no income, striving to assure quality lives for their grandchildren. We learned of the similar concerns and fears of African women who had never met, the common enormity of their loss and circumstance, and their shared determination to guarantee their grandchildren hope for the future.

African grandmothers spoke of their worries that grandchildren with HIV would become sicker and die without proper nutrition. They agonized that without education, the girls would grow up poor, fall prey to predatory males, and trade sex for illusory security. They were troubled by fears that the children might grow up emotionally unstable with all the grief, anger, and bewilderment they have experienced. Their anxiety and constant concern were all-pervasive.

Grandmothers from both continents — though often tearful — engaged in workshops with a sense of urgency. Canadian grandmothers tried to imagine losing their own children and caring for their grandchildren, but soon realized that the context, in which their African counterparts are surviving, confounds that exercise. They wondered, instead: How do these extraordinary women find the resources to be effective parents to children, some HIV-positive, who have lost both parents, and who are now watching friends, family, and teachers slip away?

The grandmothers lamented that the parenting skills they had relied upon when raising their own children, were clearly not adequate to the task at hand. In a previous generation of child-rearing, a quiet child was generally seen as obedient, whereas in the present context, a child who doesn’t cry or who is withdrawn could be suffering from deep anger or trauma or both. Grandmothers have had to add to their workloads the job of learning to explain difficult realities to young children and to assure them that they are loved.

“African tradition took it for granted that women are to look after children, to be at home — so they never bothered to take [girls] to school ... When you are educated and learned, you’ll have an earning, and with an earning, you’ll have your own decisions. Nobody will decide for you.”

“In North America, we are notorious for ‘Me, Mine, and More’ and we have got to be ‘Ours, Us and Enough.’ If I were to make a wish for any child, it would be ‘Enough’ — enough love, enough food, enough medicine, enough uniforms for school” — Barbara Coloroso

“African culture never had a word for orphan. Children belonged to everybody.”
Grandmothers told us of the differences in expectations, across generations, about how children should relate to elders. And the differences they encountered, even in understanding spoken vernacular, between children raised in towns and their country grandmothers. We heard about the need to face these new challenges, by integrating the natural and constant emotional care that children may receive from their grannies, with more formal advice and counselling. Many of the projects were providing this kind of guidance.

African grannies also pointed out that, beyond the emotional strain, providing constant stimulation and physical care to infants and toddlers is particularly demanding and exhausting for them. They gave us a glimpse of those hardships, particularly when raising HIV-positive children: the constant worry, the difficulty of administering drugs properly, the lack of money for drugs, the fear of stigmatization and disclosure (both to the child and the community), and the difficulties in getting children to the doctor or nurse on a regular basis, without transportation.

“All my children are all our children.”

As noted earlier, the subtext to many of the discussions was the grandmothers’ pervasive fear about what would happen after they died. Who would care for the children? How would they bear loss heaped upon loss? How would they recover? Who would become their parents and give them the nurturing and continuity that they so desperately need? Where would the money come from to ensure that they could continue their education? Would they be able to stay together? There are no easy answers, but the involvement of the projects made the grandmothers feel hopeful. Formally or informally, the
Grassroots projects provide some forum for discussion of these fears, as well as a place for grannies to draw together, find solutions, and assure each other that someone will always be there to care for their families.

Grannies told us of their fears that the girls in their care will be more susceptible to early pregnancy, early marriage, or other forms of sexual exploitation because of their economic and emotional vulnerability. Even with the grandmothers’ best efforts, it is unavoidable that many of the older grandchildren are already responsible for the well-being of their siblings, and lack adequate shelter and security.

We heard education raised as a preoccupation in all the workshops dealing with orphan care. African participants told us that while school fees have been abolished in some of their countries, the prohibitive costs of shoes, uniforms and books often keep children from enrolling. One grandmother described how she had lost nine children, some to AIDS, and was raising her six grandchildren. She works in the fields and brings in so little income that she can only afford to send one child to school. Another grandmothers told of losing all her brothers and their spouses, and caring for 11 nieces and nephews and one grandchild. But what sat most heavily on her mind was the fact that she had no idea how she would pay the school fees that would be due when she returned home.

“I would have liked one or two of the kids . . . to get educated and start work so that they can look after the others, in case I die. That’s why I pray and hope — that two or three can finish school and look after the others.”

The grandmothers clearly know the pivotal role of education as an escape from the poverty that could otherwise trap their grandchildren in a cycle of disempowerment, disenfranchisement, despair, and even death. But, few could afford it. The Canadian grandmothers were shocked to hear how little money it took to send a child to school — as little as US$40 a year in Malawi and under US$100 annually in Kenya — and by stories about children who shared a pair of shoes, alternating days for the long walk to school to attend classes. Grandmothers also emphasized that some schools now provide the children sugar, paraffin and cooking oil, and with the proceeds, feeds the orphans.

**Grannies’ Stories**

**Martha Ndii Mahindu**  
CABDA (Community Asset Building and Development Action)  
Vihaga District, Western Kenya

Martha speaks: “I have six children and six grandchildren. I lost two of my children to HIV/AIDS. My husband is jobless. I am part of CABDA, a group of 45 women with 180 children who are orphans.”

“Before I was just going around looking to get a job to feed the family.” Maria describes how she would often go without eating for two or three days, with nothing to give the children or grandchildren. She received a loan from CABDA, and now she takes care of her own six orphaned grandchildren and three other children who are orphaned and HIV-positive. She works in a tiny shop where she sells
with a much-needed meal, and all provide them with continuity in lives otherwise dominated by unwelcome change and uncertainty.

They stressed the importance of education beyond the primary years. "We do not want to waste brains," said one, while another added, "All our children should go to school, up to university." The grannies agreed. "Knowing that kids have hope for a better future makes it easier for us." Projects presented a number of helpful models and ideas to get girls into school and keep them there, including working closely with the whole

Ruth James
British Columbia, Canada

Ruth speaks: "To be part of the Grandmothers’ Gathering is to be entrusted with a new way of thinking. The African she-roes and their ability to connect, to break into song, ululate, and hug some of us (rather stiff, well-meaning Canadians) after sharing some of the most heart-rending life narratives, shattered our assumptions. Being a part of circular seminars, with vividly dressed women interspersed with pale Birkenstock-clad ladies who listened closely, hearing that grandmothers of Africa had survived colonialism, in some cases apartheid, loss of their adult children, and now were caring for many orphaned children with little or no resources, was like a sting ray to consciousness. Our country has been so fortunate! There is an untapped resource amongst women of our age. Beware, politicians — and maybe the male sex, too!

The kaleidoscope of the continent of Africa first crept into my heart during the late 1970’s. I was fortunate to become part of a charity with a mandate of providing African storybooks to African children.

On July 20, 2004, two tiny identical twin granddaughters came into our world in North Vancouver, Canada. From the time they were identified as late cell division twins, developing in just one amniotic sac, a team of doctors monitored their well being. They arrived early by caesarean section, surrounded by highly qualified specialists, nurses, two loving parents, four grandparents all of whom cared for and

(cont’d on p.48)
community to ensure that the importance of girls’ education is supported; making home visits to intervene with households where girls may be kept at home to care for younger children while their brothers are educated; and providing training in business skills and life skills to teach girls about self-esteem and sexual autonomy.

Finally, the African grandmothers told us, in their own heartfelt words, what they thought it meant to be an orphan. Their grandchildren, they explained, can be described as ‘orphans’ not because they are abandoned or suffer from a lack of love, care and support — on the contrary, they know that their grandmothers struggle to provide for them every day — but because they are uncertain that their need for food, shelter, education, and clothing will be met.

“I would like to celebrate the lives of these grandmothers and I would like to thank Stephen and his foundation for giving us this opportunity to commit ourselves today. Like the rest of you I commit myself to the life of that child. I will turn every stone, I will move every mountain, I will climb every hill and I will walk every mile until that child attains self-actualization and until these grandmothers get the rest that they deserve.” — Joy Phumaphi

Lucia Mazibuko  
Gogo Granny Outreach Project  
Alexandra Township, South Africa

Lucia wanted to “tell [the women at the Gathering] about myself, my family, my loss and my grandchildren and how many people I am left with. My support group helps me with my difficulties, but tell them what I’ve been through because of HIV/AIDS. I want grannies in Canada to organise grannies’ groups who are going to help us in Africa. As grannies of Africa we know we have sisters here.”

Lucia told us that when her first daughter died of AIDS in 1999 and then her second died in 2000, she was devastated. “I didn’t know anything about AIDS. I just kept quiet. I just kept the kids inside. I didn’t want to talk about it. I nearly lost...” (cont’d from p.47)
my mind,” she said. But then her grandson, Bongoni, who had been attending a bereavement group at the local clinic, got her to finally open up. He begged her, “Please talk about AIDS with us.”

Lucia is 52 years old and lives in Alexandra Township in South Africa. She is a widow and was a mother to six children. She has lost two daughters to HIV/AIDS. After their deaths, Lucia assumed the care of her daughters’ two HIV+ children, Bobo, who is now 9 years old, and Bongoni, who died of AIDS in 2004 at the age of 9. Lucia did not have the money for the antiretroviral drugs (ARVs), that her grandson needed. She became one of the first three grannies to join the Gogo Granny Outreach Project. Today she helps new members of the group, and she says that using her own experiences, she is able to counsel and support them through their pain. She describes her life at home as a constant battle for survival. Her husband is dead and she lives in a two-room home with her grandson. Her only relief is the Gogo grannies, where she can talk, grieve and learn new skills, including gardening and sewing. All together, the members are raising 172 orphaned children. In Lucia’s words, “I’m not educated, but I teach them, ‘We’ll deal with this together.’”
THE WAY FORWARD: AN OVERVIEW

“We now know we have sisters in this struggle; unified, we will make change!”
The final series of workshops focused on the way forward: advocacy and actions to be taken by both the African and the Canadian grandmothers. The closing sessions amounted to powerful statements of commitment and creativity — testaments to the expertise and wisdom of all present, and their determination to leave the Gathering having made a difference in the lives of Africa’s grandmothers and the children in their care.

Over two days, the grandmothers discussed topics ranging from fundraising to networking, from providing basic needs at the local level to advocating for increased international commitment, to gaining recognition for the critical roles played by grandmothers the world over. They utilized dozens of creative approaches: story-telling and films that generated discussions and provided information, leading to empowerment and action; songs and dances that transcended language barriers, giving room for mourning and time celebration; sharing models and providing specific examples of successful project approaches, fundraising efforts and lobbying techniques, and much more.

By popular demand, each workshop ended on a high note of mutual discovery, empathy and commitment to one another — across continents, cultures and regions. Two days of intense sharing and discussion left the grandmothers, in their final round of workshops, hugging, weeping, raising their voices together — sometimes in joyful unity and sometimes in anger over injustice — making deeply felt declarations of commitment, and feeling renewed hope and energy for the struggle ahead.

We can’t possibly cover all of the thoughtful presentations. What follows is an overview of the terrific conversations that took place.
CHALLENGES TO THE WAY FORWARD: GRANDMOTHERS’ PERSPECTIVES

• The need to have a voice in public fora — whether within their own communities or in parliament;

• Intolerance for the silencing of women and the particular invisibility of older women, which, in turn, has resulted in a global failure to recognize not only the contributions grandmothers can and do make, but the strength of their experience;

• Impatience with the many factors — ageism, sexism, poverty and the absence of the concept of an elder ‘stateswoman’ in African countries and Canada — that muffle the voices of grandmothers and keep their needs from finding their way onto the agendas of those responsible for addressing them.

Despite their awareness of all the impediments, none of the grandmothers were cowed. Instead, they saw power in their numbers and in their solidarity. As one Canadian quoted, “If you think you’re too small to make a difference, try going to bed with a mosquito!” to which her African counterpart responded, “We now know we have sisters in this struggle; unified, we will make change.” Margaret Mead was also quoted: “Never doubt that a small group of thoughtful, committed citizens can change the world; indeed it’s the only thing that ever has.”

KEY ISSUES

Issues of poverty, hunger, lack of shelter and health care that formed the backdrop for discussions throughout, fed into the advocacy and action portion of the programme.

Several workshops focused on women’s human rights. The African grandmothers talked about how much education and empowerment was needed. So many African grandmothers do not know their rights, and even when they do, they do not have the social, cultural or economic power to insist that their rights be enforced. And then, there is the enormous challenge of the lack of legal rights for women: lack of rights within marriage (which makes negotiating safer sex and refusing to engage in harmful practices next to impossible); the absence of property and inheritance rights (which often means that a baby boy has more rights to land and shelter than his mother or grandmother); the constant abrogation of the right to education for girls; and the inability to avail oneself of such basic human rights as a basic standard of healthcare and protection from abuse.

There was much discussion of how such gaps and abuses must be addressed, from empowering grandmothers through knowledge of their rights, to promoting legal and behaviour changes that will enforce those rights. There was an energetic discussion of how community-driven responses to human rights abuses can be effective, including participatory approaches, involving entire communities, in education and advocacy for women’s human rights. Coordinators from the African projects talked about the need for funding for grassroots efforts around ‘human rights literacy’, and getting communities to recognize the human rights of grandmothers, women and girls, and work to make them a reality.

There was a sophisticated analysis of international instruments for the promotion of human rights, and all of the grandmothers acknowledged the critical role Canadian grandmothers could play in advocating for greater adherence to, and implementation of, international conventions and the role of the Canadian government in this process.
In this context, in the workshops which looked at health issues, participants recognized the need for enforcing international standards of health and universal access to healthcare, including nutrition, sanitation, education and treatment, in addition to adequate care and support for those affected by, or infected with HIV and AIDS. We heard that there was a lack of data collection around the health concerns of older women, which proves particularly important with regard to HIV/AIDS and its effects on grandmothers. We also heard that inadequate programmes and laws addressing stress, violence against women, poor nutrition and lack of healthcare (for older impoverished women, HIV-positive women and others) perpetuate the ongoing violation of grandmothers’ rights to health. Many grassroots projects in Africa are addressing these issues — primarily through health education and home-based care programmes — but their effectiveness is severely hampered by a lack of financial resources.

There was much talk of the importance and power of networks, across provincial borders in Canada and within African countries, between different African countries, and between Canadian and African grandmothers. We heard that these networks don’t necessarily have to be formal; in fact, the grandmothers called upon the Stephen Lewis Foundation to help them keep one another apprised of what was being done in the follow-up to the Gathering, and to continue to foster their solidarity. The grandmothers remarked that they had come into the Gathering with various preconceived notions about what solidarity and unity mean. Through their interactions, they had deepened their understanding of what more it
could mean, and the role each could play in improving the quality of life for Africa’s grandmothers — and, in the process, for Canadian grandmothers as well. There were a series of workshops on fundraising and awareness-raising. Much concrete information was shared during these sessions and copious notes were taken by all.

Many of the grandmothers from Canada voiced a preference for either fundraising or advocacy as a strategic way of assisting African grandmothers. Some groups concluded that these were not mutually exclusive strategies, but mutual reinforcing ones. Many of the facilitators talked of the efficacy of engaging in both activities, stressing that awareness-raising is a critical component to fundraising, and that fundraising is needed to respond to the African grandmothers’ clear articulation of their needs for funds to help solve their predicaments. More than one facilitator discussed the need to undertake significant awareness-raising before trying to do fundraising, and encouraged grandmothers in Canada to be open to publicity. We heard that it helps to be realistic about how much money you can raise, and at the same time, grannies were encouraged not to shy away from large fundraising goals. Everyone agreed that it was effective to stay close to one’s roots, raise awareness and fundraise locally, and use the Gathering as a springboard for more ambitious undertakings, including working across provinces.

Several grandmothers talked about their initial wariness of fundraising, and how they discovered that it could be fun, joking that if someone asked them to join a fundraising group, they’d say no, but if asked to get together, have a good
time, build skills and support the African grandmothers, they would respond with an unqualified ‘yes!’ Some groups discussed their specific past activities, many of which brought creative ideas and the arts together with fundraising activities (selling crafts, holding concerts, etc.) while at the same time, raising an enormous amount of awareness in their communities. Everyone agreed that they found the experiences empowering; there was increased respect for their skills and they felt better understood in their communities and families and among friends.

We heard very specific and concrete advice: develop key messages; make an event plan (short term and long term); foster relationships with local and national press; identify allies in the community and pursue them; strive for diversity in your group (across experiences, cultures, ages, etc.); don’t hesitate to mobilize, act, and inspire others; and never doubt that your commitment, empathy and determination will do just that! One group advocated for starting small and letting the group take on a life of its own; another spoke of many small groups uniting and networking through a larger umbrella group.

The need to raise funds was stressed over and over. One particularly successful fundraising group talked about how they had started out ‘allergic’ to fundraising, and quickly realized that they didn’t have to do it all on their own; they could mobilize and motivate other sectors in their community and be much more effective.

The York Region Committee in Support of the Stephen Lewis Foundation, a group of committed individuals who have raised almost a million dollars in support of grassroots projects working on AIDS in Africa spoke of how they set up a speakers’ bureau, met with town councils, got their school board involved in raising awareness of AIDS in Africa, held ‘Breakfasts of Champions’ in different communities (faith communities, business, local government, etc.) and had ‘patrons’ and locally-respected guest speakers addressing the issues. As a result of this effort, grandmothers’ groups have sprung up throughout the area.

Still others emphasized: Get the word

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**GRANNIES’ STORIES**

**Alicia Mdaka**  
**Grandmothers Against Poverty and AIDS (GAPA)**  
Cape Town, South Africa

Alicia Mdaka is described by her peers as one of the dynamic founders of GAPA and known affectionately as ‘Mrs. Mdaka’. Now 66, she was a mother to eight children and grandmother to seven. In 1999, Mrs. Mdaka lost a daughter, followed by an 8-month-old granddaughter in 2000. In 2001, her home burned down with all her belongings inside, and that same year, a second daughter died. Two of her sons suffer from mental illnesses. With all of this hardship, Mrs. Mdaka had suicidal thoughts. One of her daughters has been living with HIV for 11 years and encouraged her to attend a support group. Mrs. Mdaka found an enormous amount of support with other grandmothers there, and they decided to start a group called Grandmothers Against Poverty and AIDS. The group put their money together to get her a sewing machine to replace the one she lost in her house fire, and she uses it to bring in income. “It is time for us grannies to wake up,” she says. “Together we can do it. Unity is strength! I am now a community leader!”

She lost two of her sons through violence in South Africa in the last two years, but has maintained her strength through the network of grandmothers.
out. Don’t let people forget. Always include an educational component to your meetings and events. Get your name out there. Engage in different kinds of initiatives, such as vigils and partnerships with schools; target important dates such as World AIDS Day (December 1st) and Grandparents Day: the funds will flow, and so will attention within the community. Finally, there was much excitement from several Canadian groups about inter-generational work — engaging young people through schools and joint awareness-raising and fundraising activities — to mirror the inter-generational support that grandmothers provide when they care for their grandchildren.

Awareness-raising was also energetically discussed in the context of advocacy at the national level. Both African and Canadian grandmothers talked about the importance of lobbying governments to change policies; to recognize the needs and rights of African grandmothers; to make their issues more visible, and to include them in research and political solutions. Canadian grandmothers spoke urgently of the need to push

Sharon Swanson
Perth, Ontario

I am a 64-year-old married woman from Perth, Ontario; a proud mother of four and grandmother of six.

Unlike many African grandmothers, I have never gone to bed at night worrying about how I might find food for my grandchildren. I have never wondered how I might find the money to pay for school fees so they might learn to read and write. Nor have I ever watched any member of my family suffer with dreadful pain, knowing that neither medical help nor medicine was available. I have seen my children through illness and sad times but I have never had to bury my child. I have lived a privileged life.

Growing up in Vancouver East, I was frequently reminded by my parents (who had very little) of how lucky I was, how it was my responsibility to help those who were not so fortunate. I felt then that they just didn’t get it, but over the years, various experiences helped me to see things from their perspective.

The Tsunami tragedy helped me to appreciate that I was a part of the global community, not just a resident of Canada. I felt that we were all in this terrible tragedy together — responsible for each other and the planet. Listening later to Stephen Lewis deliver the Massey Lecture series provided me with the opportunity I needed. I headed eagerly to the gathering of grannies in Toronto to learn more. It was a moving, inspiring and sad time. I wanted to support the grannies in Africa in some way. I knew that family and friends were all busy and already committed to other important endeavours in their communities. Hoping that they could find a little time, energy and money to support the courageous grannies

(cont’d on p.58)
in Africa and believing that together we could make a contribution, I sent out a letter asking for their help:

(An excerpt from Sharon’s letter):
“These 100 grannies are heroines. In the small workshops, they told their stories. I could hardly bear to listen at times. Small, frail, and wizened elderly women, robust, young, exhausted women repeated the same story:
“I had 6 children, only 2 are left now and one is ill.”
“I have seven grandchildren to care for. They are good children but I cry at night when I have no food for them.”
“Every day I work in the garden, sometimes I have potatoes and beans to sell but usually not.”
It went on and on. The goal was to help Canadian women understand what it was like to bury your children, and then in your 60’s and 70’s, have to start again to do child rearing. I know I was constantly wiping tears from my eyes as they stopped in their stories to weep. And yet, it was not a sad time. Believe it or not, they always had something positive to say. They always had a smile when they got themselves composed and they broke into song and dance at a moment’s notice. They were truly unbelievable. I do not have words to describe them to you.

Canadian grandmothers agreed that lobbying gives women a voice. They talked about using all at their command — networking through the internet, calling MPs, calling for face-to-face meetings, letter-writing, and targeting their actions to ensure maximum effectiveness. They noted that one can’t hold governments accountable alone. AIDS in Africa has a woman’s face — so grandmothers are logical advocates.

governments to meet the commitment, made long ago, to allocate 0.7% of the country’s Gross Domestic Product (GDP) to foreign aid.

An African grandmother, facilitating a workshop on the silencing of grandmothers said, “There must be relentless advocacy for government programmes and change.” She stressed that African grandmothers are not silent because they have nothing to say, but because their culture silences them. They must be supported to speak and be heard.

GRANNIES’ STORIES (cont’d from p.57)
POST-GATHERING UPDATES

“We are so inspired now, so I hope every one of our grannies will keep up the good work and never give up... we can do it!”
In Africa, much networking and organizing has begun and is being continued. We continue to hear from groups all over Africa, including some who attended the Gathering and others who did not. They are all expanding or beginning programming around support to grandmothers. Here are just three fascinating developments that illustrate the power of the experience at the Gathering, and the opportunities for further mobilization and solidarity-building. Each is garnering support for the unsung heroes of Africa: the grannies.

1) In South Africa, GAPA (Grandmothers Against Poverty and AIDS) is planning an exchange with SWAPOL (Swaziland Positive Living for Life) in Swaziland. They will meet with the members of SWAPOL (which was represented at the Gathering), in order to continue the conversation started in GAPA’s workshop about how to replicate successful models in other countries and contexts. This is an exciting development initiated of their own accord and facilitated by the groups themselves. Please see p.89 of the Supporting Documents section for GAPA’s paper on their genesis, model and successes.

2) In November 2006, several Kenyan groups that attended the Gathering (PDI WOSP, KWOSP, WOFAK, TAPWAK and MORCAO) held a joint meeting to form the Network of Grandmothers Caring for AIDS Orphans (NGAO). They have agreed that every province in Kenya will have an organization that is a focal point for the network, and they are moving to have their group officially set up as an NGO in Kenya!

3) The Chiedza Child Care Centre (CCCC) in Zimbabwe assists orphans and other vulnerable children and caregivers affected by the HIV/AIDS pandemic. The CCCC runs after-school programmes, nursery schools, women’s support groups, wage-earning activities, community gardening and training for community caregivers. They provide support to grandmothers working to care for their grandchildren and other loved ones affected by the pandemic. SLF recently received an update from Stella Masikano, Executive Director of the Chiedza Child Care Centre. What follows is a story like hundreds of others, but we want to share it with you in detail as an example of how the impact of the Gathering continues to play out in the work of the Foundation:

One of the Grannies was locked up in prison to serve 90 days for failing to vacate her late mother’s house where she and her husband were caring for an orphan left by her late sister. Her husband was terminally ill. We got to know about all this through the ill husband who was asking us as an organization to take this orphan to our centre. As you know we are a community-based organization, although we have few buildings, we encourage children to stay within the community.
We visited the sick husband as a team from the centre and, hey, the man was in so much pain, without food and nobody to really care for him since the wife is in prison.

When we left the house, which is 20 kilometres from where the family used to live, and this is in a different town from Harare, we thought of alternatives to keep the child in school. The child had missed lessons for a whole week because he could not afford bus fare. We then visited the Grannie in Prison and asked if she was comfortable with the idea of having the orphan placed with Grannie Dorcas who attended the workshop in Toronto, she agreed happily. We were not sure if Grannie Dorcas would accommodate this extra child as she already has 23 people in her household, but because of her outgoing personality and kind heart, we thought we should give it a try. It was only one word and she accepted. This was the best place for the child to be because its in the same neighborhood and the child is friends with some of the children within the household already. When Grannie Dorcas accepted this request, I couldn’t hold back my tears. Meanwhile the husband of this granny in prison got worse. We went and removed the child from that household and the child resumed lessons at school. Most importantly, he has settled down very well.

Sadly, the sick husband passed away on Wednesday 27 September 2006. Since there is a problem of fuel shortage we could not attend the funeral but we only managed to provide bus fare for Brian, the 13 year old orphan. He has since gone back to Grannie Dorcas. The Grannie in prison could not even attend her husband’s funeral. She herself looks ill.

What it means is that we are going to have additional children to look after.
I thought I should share this with you.

Kindest Regards
Stella

The SLF wrote back to Stella, asking her to let us know what kind of funds the grannies need to get them through this hard time, as a group and as individuals.

Stella wrote back:

Hi Ilana
Many thanks for your email. I feel so much relieved to know that other people care. Thank you so much Ilana. Just hearing from you has made such a big difference. Yesterday i went to the prison to visit Mary Makoni as we had not seen her since the husband died. She only knew about the husband’s death three days after the burial. I went with two of my staff members and it was such a moving occasion to all of us. The reason why we also wanted to see her was to prepare her for the future: to find out what she was going to do after serving the sentence, what her plans are for the children and where she would go upon release. She asked me to ask Grandmother Dorcas to look for a two roomed accommodation so that she can reunite with her two children and Brian.
Definitely she would need the basics like accommodation, food and toiletries.
Granny Dorcas was even prepared to let Brian stay until end of next year when he completes his O Levels.

NOTE FROM SLF:
As a result of this correspondence, Chiedza is putting together a proposal to address the needs of grandmothers in their community. Granny Mary Makoni has been
released from prison and united with Brian at the Chiedza Centre. She is staying with a distant cousin, and as part of the Chiedza ‘granny project,’ she will be funded by the SLF to help her put her life and her family back together with adequate resources and shelter.

Dr. Stella writes: When Granny Mary Makoni met with Brian at Chiedza Centre, it was a moving ceremony as the two embraced each other. Granny Makoni spent the whole afternoon with us and the other grannies that had come to the usual support group meeting and to welcome her. She started unwinding and there was visible shakiness in her speech until much later in the day when she realized that she had been accepted back in society.

UPDATES FROM CANADA

Since the Grandmothers’ Gathering in August, another 90 grandmothers’ groups have formed across the country — bringing the total number of groups raising awareness and funds for African grannies to over 140, and there are more in the works!

There have been so many innovative and committed activities to raise awareness and funds — those below are just a small sample. In 2006, the Grandmothers to Grandmothers Campaign raised over $600,000!

GRANDPARENTS DAY ON PARLIAMENT HILL
Patti Koeslag of Grands & Friends in Ottawa, Ontario

On September 10, 2006, grandmothers’ groups from Ottawa and the surrounding area marched together on Parliament Hill — the seat of Canada’s federal government — to raise awareness of the costs of HIV and AIDS for grandmothers in Africa. They plan to make the march an annual event!

Here are their plans for next year’s Grandparents’ Day March:

October 21st email:
Sep. 9, 2007 (Grandparents Day) will be our second annual march on Parliament Hill on behalf of the Grandmothers of Africa. All the Ottawa groups and some outlying groups will be participating in the organization of this. We will be putting out press releases and have some very capable lobbyists and public relations people on our team. We have a multi-group planning meeting scheduled for early in the new year.

We have been in touch with some African vocal groups (Voices of Africa, USA) and would like to set up a Saturday evening engagement with speaking and entertainment and a Sunday march and speeches on Parliament Hill.

We are thrilled to tell you we made $900 on our yard sale and then we received another cheque for $1,000!!! As well, the Green Door Restaurant is looking at Nov. 27 for a dinner fundraiser... I think all the groups in the area are going to get together on this...all monies go to SLF.
INSPIRATIONAL BENEFIT CONCERT
Barbara Sivorot of Creston Gogo Grannies in Creston, British Columbia

October 24th email:
The first annual Benefit Concert held by the Creston GoGo Grannies was held at the Prince Charles Auditorium on September 30th. It was a huge success, raising over $1600.00 for the Stephen Lewis Foundation (less a little for expenses!). We had 12 entertainers, who volunteered to assist us. We had mostly singers, but also had a wonderful piano player, Monte Anderson, accompanied by his daughter, Sarah Anderson, playing a fiddle and Karl Sommerfelt, also on the fiddle. Also a group called Wild Mountain Thyme from Bonnersferry in the U.S.A. who sang their hearts out. It was a wonderful evening and I wish you could all have been there. At the beginning our President, Ingrid Voigt, gave a opening speech on who we were, our cause and it went over very well. We even dressed the part, and had the most unique African gowns to wear. Donated to us by one of our members who is from Africa. We also sold many of our items that help us raise money, tote bags with our GoGo Logo, and cookbooks and all occasion cards.

I could go on & on. The best part was raising awareness of the HIV pandemic and the help that is needed. We are so inspired now, so I hope everyone of our Grannies will keep up the good work and never give up... we can do it! We have a GoGo man in our group. Did he ever work hard at our concert.

Thanks for reading this....and keep in touch. Hugs to all.
Barbara Archibald, Creston GoGo Grannies
PURSES RAISING FUNDS

October 23rd email:  
My name is Lisa Jo Sun Walk and I am a grade 11 student at Sequoia Outreach School in Gleichen, Alberta, Canada. I am 18 years old and I have a 6 month old daughter named Aiden. Earlier this year I learned to make purses. I am also good at beading and other traditional art. (Did I mention that I’m a member of the Siksika Nation - Blackfoot tribe of Southern Alberta).

I am now teaching other kids at my school how to do this. I will earn credits in school also. My teacher told me about the ‘Grandmother to Grandmother’ program and I thought that we could make basic purses and then invite our Grandmothers in to help finish them. This way we would form our own Grandmother to Grandmother group. I think we could donate our purses to the Calgary group who sells their work a few times a year. Would it be OK for us to do this?

On our reserve Grandmothers are so important. We also lose lots of our young parents to the effects of poverty, drugs and alcohol. Even though our lives are sometimes hard we think they’re not as difficult as those Grandmothers in Africa.

Thank-you,  
Lisa Jo Sun Walk

ELLEN MONAGHAN OF UJAMA GRANNIES IN CALGARY, ALBERTA

October 18th email:  
Our sale was a resounding success and we were all absolutely delighted with the crowd and the overwhelming comments of support. We sold out before noon hour but even those who came later often stayed for coffee and a chat. The best part of the whole sale was that people were so interested in what we are doing, in the Stephen Lewis Foundation and in the situation in Africa. We have a wonderful list of new people who would like to become purse producers or volunteer for general fundraising so the future looks so exciting.

We had 181 items for sale (If only we had been able to produce more we would have been able to sell so much more — next year!) and took in just over $8,100 with sales and the coffee bar. We are looking at expenses of approximately $1,600 — pay back for our producers and $100 hall rental- so shall have profits of over $6,000 to send to you plus some other profits from bags sold individually over the past few months.

We are having so much fun doing all this and we are growing by leaps and bounds. Was at a large high school yesterday to work out a plan with the fashion and design teacher who wants to get all her classes doing a “bag” assignment — the students seem really keen — and have enquiries from another high school to do the same. It would be wonderful to get some young people involved and thinking about Africa.

Take care,  
Ellen
SUPPORTING DOCUMENTS

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Gathering Workshop Descriptions

Reprinted directly from the Grandmothers’ Gathering programme.

A Grandmother’s Life in Zambia: Coping with HIV/AIDS and Poverty

This workshop will give some insight into the lives of grandmothers in Zambia before and after the pandemic of HIV/AIDS. Participants will explore, individually and collectively, how their skills and knowledge can help them cope personally, and help their families and sister grandmothers. Small groups will present their findings to the workshop and together will develop ideas for action to bring home. This workshop will feature games and songs to help participants get to know each other.

A Tale of Hope and Development in an Environment of Poverty, Sickness and Death

At this workshop, grandmothers will share stories about the deaths of their children, their feelings of hopelessness and helplessness, and their subsequent leadership roles in the fight against the effects of the AIDS epidemic in their communities. The presenters were founding members of Grandmothers Against Poverty and AIDS (GAPA) and will describe its progress, successes and lessons learned — offering a blueprint for intervention for grandmothers living in similar environments. The workshop will incorporate drama, singing and visual aids, to showcase a positive African spirit.

Build With What You’ve Got to Promote Networking and Cooperation

This workshop will look at the impact of cooperation, networking and communication on the success of development projects. The workshop includes facilitated exercises with four groups of 6–8 participants, followed by a discussion and sharing of information. Boxes of assorted materials such as pieces of cloth, coloured paper, pipes, tools, sticks, bottles, and tins will be used for the exercises.

Building a Functional Community of Grandmothers and their Dependents — A Road to Meaningful and Sustainable Livelihood

Grandmothers have proven to be committed, loving and effective caretakers of orphans, dependents and their sick children. However, many of them have little or no education, and limited access to medical care and other social services. These obstacles reduce their visibility in society and their involvement in community development and service delivery. That’s why it is imperative that strong networks of grandmothers and their dependents are nurtured and supported. In this workshop, we will discuss culturally appropriate means, skills and knowledge to mobilize and organize influential and durable action groups.
Building Resilience in Children and Older Caregivers/Grandmothers

AIDS orphans can lose their home, self-image, material well-being and even their status as a child. They are often cared for by grandmothers and other elderly relatives who do not have the knowledge or skills to deal with a child’s complex emotions in a time of loss. However, older caregivers have great life-experience and wisdom, and helping their grandchildren build resilience and cope with their loss in turn builds self-esteem and resilience in the grandmother/caregiver. This highly-interactive workshop includes short presentations and activities that develop simple behavioural and communication skills. Grandmothers will learn how to make Memory Books and Memory Boxes.

Caring for Children Living with HIV/AIDS

This workshop will begin with a grandmother’s story and role play about caring for HIV-positive grandchildren. The second part will feature a presentation by a professional on how to care for children living with HIV. Topics will include: how to monitor growth, promote nutrition, treat infections, get immunizations, and provide ongoing psychosocial support for the child and the caregiver. The workshop will conclude with a question and answer session.

Challenges Faced by Grandmothers in Northern Uganda: A Case of the Acet Internally Displaced Peoples Camp (IDP)

This workshop begins with a brief description of the TII KI KOMI women’s group by its Chairperson and founder, Balbina Akidi Okot, followed by a story from Santina Akello, a 71 year-old grandmother, about the challenges she faces caring for twenty orphans and vulnerable children. There will also be a video depicting a typical day in the life of the Acet IDP inhabitants, after which participants will form small discussion groups to identify positive coping strategies and lessons learned. The workshop will finish with miming an Acholi traditional dance.

Challenges for Grannies

Grannies, especially those caring for orphans, lack financial and social support, and the resources to meet their own needs, along with those of the children they sustain. Moreover, they are already battling challenges related to gender and age discrimination. This workshop will discuss how to help grandmothers gain access to their legal and social rights, including social protection programmes and other entitlements, such as property inheritance, child welfare grants, access to education, health care and other social services.

Challenges and Coping Strategies Around Lack of Food, Clothing, Housing and School Fees

This workshop looks at how to put together and launch a campaign that provides long-term, sustainable material support (including food, clothing, housing and school fees) for children infected and affected by HIV and AIDS and their African grandmothers. Such a campaign would enable grandmothers and programme managers to develop skills and apply the principles of sustainability in self-help programmes, using principles of problem analysis, planning and implementation, financial and human resource development, and
Counselling and the Put-Down Syndrome

This workshop looks at the effects of counselling and the ‘Put-Down Syndrome’ on orphaned children. The ‘Put-Down Syndrome’ is what orphans experience when they are constantly told they are inferior or lazy, comments that often come from teachers who lack understanding or empathy for the child’s situation. At the Friends of Claude Ho in Thylolo Association (FOCHTA), counsellors try to show orphans that people care for them and understand the almost insurmountable problems orphans face every day.

Dealing with Depression and Grief

In this workshop, the GoGo Grannies from Alex township, South Africa will talk about the journey they have taken as grandmothers dealing with the impact of HIV and AIDS. They will be sharing their specific experiences and what they have learned about supporting each other over the years. The workshop will also identify stages and steps of grief.

Facing the Challenge: KWOSP Grannies Experiences

This workshop looks at the experiences of the grannies affiliated with the Kenya Widows and Orphans Support Programme (KWOSP). It will be divided into three sessions: 1) grannies living with AIDS and struggling to meet the basic needs of the orphans under their care; 2) leadership in old age; and 3) stigma, discrimination and cultural beliefs.

Family: Including issues of orphans and the Elderly

St. Francis Health Care Centre works to bring together mentors in the community with children affected by HIV/AIDS. The aim is for the mentors to create a sense of belonging and provide guidance to these children after their parents die. This workshop will explore the programme model run by the Centre in Uganda, with recommendations on dealing with orphans and the elderly in the context of HIV/AIDS, including issues related to reproductive health.

GAPA: The Way Forward

Mandisa Mafuya, a member of Grandmothers Against Poverty and AIDS (GAPA), will facilitate this workshop. Topics will include: how grandmothers cope with the growing numbers of deaths and HIV infections in their communities, the growing network of grandmothers, strategies on coping with death and traditional rituals in South Africa. Other topics that may be discussed include caring for the sick (from a non-medical perspective), and the care of orphan grandchildren.

Grandmothers Forgotten

This workshop will discuss the position of grandmothers in the community and the challenges they face in caring for orphaned grandchildren. The session will focus on the grandmothers’ struggle to provide food, clothing, housing and school fees (amongst other things) for the growing number of orphans under their care, without encouragement or support from society. The workshop will also explore how society can support grandmothers’ changing roles so that they can provide for the orphans under their care.
Grandmothers: A World of Hope

Grandmothers have come to symbolize a world of hope for countless numbers of children orphaned by HIV/AIDS. If grandmothers were not available, what would have become of the children of our children? This workshop begins with an introduction and a short skit followed by brief testimonials by two grandmothers on the theme “Grandmothers: A World of Hope.” The session concludes with a short mimed skit demonstrating hope for the future.

Grandmothers Lobby to Put an End to AIDS in Africa

The workshop will begin with a short presentation on lobbying and advocacy followed by a discussion of grandmothers’ personal experiences with lobbying. Participants will then break into three groups and work with one of the following: 1) Canada’s commitment to AIDS in Africa and lobbying for the 0.7%. 2) Lobbying for the proposed International Women’s Agency; 3) Using role play to prepare a presentation to the Canadian federal government. A committee will then be struck to ensure follow-up after the Gathering.

Grannies Make Cents—A Joyous Partnership

The Wakefield Go-Gos will describe, in words and with a slideshow presentation, how they formed one of the first grannies’ groups in Canada and were able to engage their community in various fundraising events. Participants will be asked to identify their own fundraising ideas, and will have an opportunity to develop a communications or publicity strategy.

Grief Counselling for Grandmothers and Children Under Their Care

This workshop will help grannies understand the stages of grief as well as the different reactions to bereavement, types of grief, factors influencing the magnitude of grief and reasons why grannies or grandchildren may experience a failure to grieve. The workshop will include role play, discussions, and information on the need for grief counselling and the different methods of assisting a grieving person/child. The workshop will use various learning aids such as stones, photographs, flowers of different colours, symbolic pet pictures, books, newspapers, money and clothing.

Grieving and Mourning in Children

This workshop will explore the concept of bereavement and the grieving process of children. The session aims to foster a greater understanding of the stages of grieving so that caregivers / grandmothers will be better able to understand and support the child as they cope with their loss. The workshop will include practical tasks for dealing with grief.

Health and Education for Orphans and the Role of Grannies

This workshop — using the experiences of grandmothers — will combine a presentation, role playing, and plenary discussion on how four regions (Canada, Europe, Africa and Asia) define the health and educational needs of children. Participants will then break into four groups to discuss challenges and possible recommendations for addressing those challenges. The workshop will end with a song from the grandmothers and a call for future workshops on this issue.
Health Issues

In June 2006, the UN adopted a Political Declaration on HIV/AIDS that commits governments to provide support to older people in their role as caregivers. However, the declaration fails to recognize that a substantial proportion of adults living with HIV are 50 years and older. This workshop will explore the situation of African grandmothers in terms of their own health, their HIV status, prevention of transmission and treatment. We will also discuss the need for financial aid to grandmother caregivers, especially those who are infected themselves.

HIV and AIDS Introduction

This workshop will focus on how grandmothers can take care of themselves and how grannies can contract HIV. Discussions will include: precautions that can be taken to prevent HIV transmission, the differences between hospitals/clinics vs. traditional healers, teaching in our communities, and understanding how to use prophylactics.

HIV/AIDS Introduction: Understanding the Impact of AIDS

The aim of this workshop is to convey key elements related to the HIV/AIDS epidemic, including: the three waves of the epidemic, HIV illness and death associated with AIDS, and the impact of HIV/AIDS. Following the presentation, participants will break into groups to discuss ways forward and establish priorities for future action.

Human Rights Voices

The workshop will present several stories of women who have worked for human rights in their areas, with a particular emphasis on the rights of orphans and grandmothers. There will be opportunities for the people in attendance to share their own stories.

Interactive Storytelling as a Community Builder and Revival

In this workshop, participants will share stories that are rooted in African traditions and have universal applicability. Participants will act out characters and analyze the setting, the theme, the problem and the solution — highlighting positive values and how the stories relate to everyday life in our communities.

Lighting the Fire!

This workshop will focus on how to mobilize a community for fundraising activities, based on the experiences of the York Region Committee in Support of the Stephen Lewis Foundation’s “If I Had a Million Dollars Campaign” to raise funds and awareness of the AIDS pandemic in Africa. The session will provide ideas and concrete examples of what worked and what didn’t work during our campaign. It will also focus on the connection between Grandmothers and youth. The workshop includes a PowerPoint presentation and two short videos.
Older Carers Need Time to Relax and Interact with Peers for Effective OVC Support

The workshop will talk about the benefits of the group process as a means of alleviating stress and providing social support. As caregivers, grandmothers need time to relax and interact with their peers for effective support. This workshop aims to help the grannies appreciate the value of sharing with friends as a means of relief and healing, so that they can better look after the orphans in their care.

Playback Theatre: Trading Our Stories

Playback Theatre is a form of improvisational theatre where the teller of the story, the actors and the audience are all part of a mutual sharing. We get to experience how our stories link to one another, weaving us all into the same cloth. Participants will begin the workshop with some simple warm up exercises. Then we will share some of the stories which emerge from our reflections, and take turns playing these stories back in the simple ritual forms of Playback Theatre.

Prevention of Mother to Child Transmission (PMTCT)

This workshop focuses on how to prevent transmission from an HIV-positive mother to a child. It looks at modes of transmission, what you need to do if you suspect you are infected, and who is eligible to participate in the Prevention of Mother to Child Transmission program. The session will review some of the major impacts and challenges, particularly in rural areas where there is little to no understanding about the disease.

Poverty and HIV/AIDS in Africa

Poverty is real in the households of grandmothers who have traditionally used their income to educate their children with the expectation that their children will support them in their old age. Sadly, many of these children have died of AIDS and grandmothers must relive the parenting role with their grandchildren and struggle on less than a dollar a day. This workshop will explore the impact of poverty on grandmothers coping with HIV and AIDS and will propose a number of ideas to improve their livelihoods.

Putting a Human Face on Publicity

This workshop will focus on the importance of publicity and awareness in helping grandmothers in the fight against AIDS. The session will look at lessons learned in using publicity, communication, and networking to form the G4G group, raise awareness in the community and fundraise to help grandmothers in Africa. Participants will share fundraising and publicity ideas that have been successful in raising awareness and money.


This workshop will give grandmothers an opportunity to talk about the financial and social needs they have in their expanded role as the caregivers of orphans. How can their experiences be used to create stronger and broader networks of support? How can they be used to sustain a mutually beneficial relationship between grandmothers and their grandchildren in a social context that has been eroded by the negative impacts of HIV/AIDS? Participants will also discuss how to identify funding
opportunities and develop project proposals.

**Sharing the Experiences of Raising Good Children**

In this workshop, three leaders will share their experiences in raising their grandchildren, the struggles they have faced, and how they have dealt with, overcome or continue to struggle with particular challenges.

**Support for Orphans and Vulnerable Children**

This workshop involves a short talk about the presenter’s work with orphans and vulnerable children, and a brief video of her work with street children, displaced people and those affected and infected with HIV/AIDS. She will also discuss her experiences mobilizing grandmothers, grandfathers and other caretakers to care for orphans.

**Supporting Orphans and Other Vulnerable Children (OVC) to Cope with Depression, Frustration, Stress and Building Self-reliance and Support**

This workshop examines the ability of children to cope with trauma and the role of the caregiver (grandmother) to support that recovery process. During the workshop, participants will learn about resiliency development in children devastated by HIV/AIDS, the experiences of grandmothers who have actively witnessed the process, and how they supported the healing process.

**Talking About Solidarity**

As the first workshop that everyone attends, grandmothers will prepare to discuss solidarity in the context of their own experiences, within countries, and across borders. It is the only workshop in which participants have the opportunity to network within their regions. In order to facilitate this, there are four workshops for African participants, and six workshops for Canadian participants. Everyone will be encouraged to participate in open, two-way communication and mutual respect for differences throughout the Gathering. Participants will also discuss expectations, and explore what solidarity means in a North-South context — including building capacities, exchanging critical information, and building political and support alliances and networks during the Gathering and beyond. Please refer to the back of your nametag to identify which room you will be attending.

**The Bambanani Programme for Children Infected with HIV and their Caregivers**

This interactive workshop introduces the Bambanani Programme developed and conducted at Ekupholeni Mental Health Centre, South Africa, through a combination of presentations, illustrations, testimonies and role playing. The Bambanani Programme serves both HIV-positive children and their caregivers (often, but not always, grannies). It focuses on issues around diagnosis, disclosure, living with HIV, grief, and caring.

**The Behaviour Change Process**

This workshop will help grannies understand what behaviour is, what
influences behaviour, why some people find it difficult to change their behaviour and possible ways of helping oneself as well as others in the process of changing their behaviour. The workshop will include exercises and role playing.

The Forgotten Voices of Africa

This workshop will explore the real profile of grandmothers taking care of grandchildren or dependents in Africa: they are not only elderly women but also middle-aged women who have grandchildren before the age of 40. The workshop will have a brief presentation, a testimonial, and finally an open discussion where participants from either Africa or Canada are welcome to share their experiences and stories.

The Great Granny Revolution: The Rough Cut

The Great Granny Revolution is a documentary that follows a group of women in Wakefield, Quebec as they respond to the AIDS pandemic in a personal and inspiring way. Partnering with South African women at the East Bank Clinic, the Wakefield Grannies provide financial and emotional support for grandmothers raising AIDS orphans. The filmmakers will be available after the film to answer any questions from the audience. For additional information refer to their website www.rooneyproductions.com

The Journey of My Life

Participants will reflect on the ‘ups and downs’ they have experienced in their lives and how HIV/AIDS has impacted the growth and development of their families. They will have the opportunity to share information about the major challenges they have faced as grannies, their coping mechanisms and the way forward. Each participant will use colours, crayons, pencil and paper to draw the journey of her life and will share their stories and pictures in pairs or small groups.

The Role of Global Economics in the AIDS Crisis

This workshop explores the relationship between the global economy and the spread of HIV/AIDS, in particular the impact of structural adjustment programs of the World Bank, the IMF and the trade bodies. The session will examine poverty as an ongoing problem that has not been adequately recognized and addressed in the context of HIV/AIDS.

Traditional Songs

The objective of this workshop is to share the experiences of traditional songs, and to develop ways of preserving them. After a brief introduction, the participants will sing a song based on traditional folklore, interpret its meaning and explore its function. Participants will have the opportunity to discuss traditional songs from their own communities, the impact these songs have on society, and the need to preserve them.

Understanding and Challenging HIV Stigma and Discrimination

This workshop will feature participatory exercises to deepen understanding about the stigma of HIV, help participants look inside themselves at their own attitudes, feelings and behaviour, build ownership of the problem, and develop practical strategies for challenging stigma.
The workshop will use action songs, picture discussion, reflection, and other exercises. The workshop will include exercises from the toolkit (Understanding and Challenging HIV Stigma: Toolkit for Action) developed by AIDS activists in Africa.

**We’ koqma’q Qewiskwa’q Drum Group**

This workshop involves a performance by the We’koqma’q Qewiskwa’q (“way - go-mah oo-wees-kwa”) Drum Group, made up of six women, several of whom are grandmothers actively involved in raising their grandchildren. The workshop will begin with the group smudging themselves and their drums, as both a cleansing and an acknowledgment of the Creator whose Spirit infuses the songs and the Drums. Woven in between the songs will be the translations and explanations of the teachings the songs contain. The session will include some instruction on how to drum and sing.

**Where To From Here?**

How will we take advantage of all the wonderful energy, excitement and commitment that the Granny Gathering has inspired? This workshop is designed to help us come up with some plans for what can be done after the event is over. African and Canadian grannies will develop a vision for where we want to go and then come up with some concrete priorities and ideas for making our vision a reality. The workshop will be interactive and use a creative drawing technique to develop our vision. In order to make this workshop most effective, it is hoped that a mixture of African and Canadian grannies will attend.

**Why have Grandmothers Been Kept Voiceless?**

This workshop will address the issue of why grandmothers have been kept voiceless, powerless, and vulnerable within the context of HIV/AIDS in Africa, and what is being done about it.
African Participants

The African projects participating in the Gathering are community based groups which provide critical support at the frontlines of the AIDS pandemic. Grandmothers — who play a central role in the survival of their communities and the children in their care — are an integral part of this work.

*Descriptions of African projects have been reprinted from the Gathering programme*

**KENYA**

**Bomu Medical Centre (BOMU)** in Mombasa has developed a highly successful HIV/AIDS programme and comprehensive care centre which provides voluntary counselling, pre & post-test support, treatment, outreach, community education, and services for youth.

*Participants:*
Caroline Mwaka Cherokewa
Asia Ali Ismaek
Henrietta Malembwa

**Community Asset Building Development Programme (CABDA)** in Kakamega supports orphans with food and school uniforms. In addition, they train the children’s caregivers in business management and the profits from their small businesses are used to meet the needs of the orphans.

*Participants:*
Ephy Imbali Munameza
Martha Ndui Mahindu
Dinah Mukaji Isiye

**Kenya Widows and Orphans Support Programme (KWOSP)** in Awasi-Nyando provides palliative and home-based care to people living with HIV/AIDS to reduce the suffering in the family. KWOSP also offers training, grants and loans to widows (many of whom are grandmothers) so that they can start up and sustain income-generating activities.

*Participants:*
Susan Diang’a Olero Koyoo
Mary Adhiambo Nyakure
Agnes Acheng Amimo

**Kazi Mashumbani Development Programme (KAMADEP)** in Kisumu works with rural women who have been affected and/or infected by HIV/AIDS by providing them with business training and micro-credit. The organization also provides clean water to school children and contributes to the building of local capacity.

*Participants:*
Morris Munameza

**Mother’s Rural Care for AIDS Orphans (MORCAO)** in Nairobi provides orphans, vulnerable children and their caregivers with the support they need to deal with their bereavement and the skills to enable them to be economically sustainable.

*Participants:*
Jenipher Oluch Otieno
Martha Agwa
Mary Awino Onditi

**Participatory Development Initiative (PDI)** operates in the low/no-income areas of Nairobi. Through community education and advocacy, PDI works to eradicate the stigma associated with HIV/AIDS. More concretely, PDI helps widows, orphans and PLWAs gain access to basic education, social services and economic opportunities.
Participants:
Sarah Simiyu Kisaka
Joyce Kageci Gichuna
Roselyda Orwa

RIPPLES International in Meru promotes the physical, social, emotional and spiritual well being of orphans and vulnerable children (and their families) through training, education, counselling and rehabilitation. RIPPLES also promotes the rights and interests of every child by mobilizing the community to help children in distress.

Participants:
Mercy Chidi Ogbonna
Elizabet Mukiri M’njogu
Maria Wangari Mitonga

The Association of People with AIDS in Kenya (TAPWAK) is a national non-governmental organization that provides emotional, social, economic and medical support — and hope —to its members and others who are experiencing rejection, stigmatization and discrimination due to their HIV-positive status.

Participants:
Lawrence Otieno Odiembo
Zubeda Jaffer
Teresia Aoko Raduk

Women Fighting AIDS in Kenya (WOFAK) is a national non-governmental organization that empowers, supports and cares for women and children living with and affected by HIV/AIDS in a non-discriminatory and holistic manner. WOFAK’s uniqueness lies in the fact that 80% of their staff are HIV-positive women.

Participants:
Dorothy Obare Onyango
Maria E. Nakhubali Osogo
Catarina Nerima Ogombo

MALAWI

Consol Homes Orphan Care in Namitete, provides a broad range of support for orphans and caregivers — from childcare centres to school fees, from skills training to recreation facilities. They also run a widows and grannies group, which meets regularly to support each other and carry out income-generating activities.

Participants:
Alfred Chapomba
Yasinta Chapomba
Zelesi Mlatho
Nelia Mumba

Friends of Claude Ho in Thyolo Association (FOCHTA) in Thyolo provides funding for secondary school meal programmes, school fees, clothing and other necessities for children infected and affected by HIV/AIDS. They also operate a small loans programme for families, and a referral service on the availability of anti-retrovirals.

Participants:
Zione Matale
Elizabeth Mayenda
Linely Muula

MOZAMBIQUE

Kukumbi Organization for Rural Development in Kukumbi is currently spearheading two projects. The first aims to reduce the psychological and economic impact of HIV/AIDS on children, families and people living with HIV/AIDS. The second aims to reduce new infection rates through education and changes in behaviour.

Participants:
Angelo Amaro
Maria Virgilio
Arinda Bonde

NAMIBIA

Catholic AIDS Action (CAA) in Windhoek, works closely with faith-based communities in four areas: home-based family care and counselling, youth edu-
cation and prevention, care and support to orphans and vulnerable children, and voluntary counselling and testing. Services are available regardless of religion, race, background or economic status.

**Participants:**
Rachel Francis van Rooi
Sophia Vries
Emma Kasenda

**RWANDA**

**Rwanda Women’s Network (RWN)** focuses on four core programs to improve women’s welfare. They provide health care and support through the Poly-clinic of Hope and the Village of Hope, education and awareness programmes on HIV/AIDS, training in human and legal rights, and socio-economic empowerment, networking and advocacy.

**Participants:**
Knight Eugenie Kabatayi
Laurance Mukamurangwa
Beatrice Semana

**SOUTH AFRICA**

**Cotlands** has evolved from a paediatric AIDS hospice into a shelter for abused, abandoned, HIV-positive, and terminally ill children from birth to nine years of age. At present, Cotlands is serving eight communities, reaching more than 1,500 families, by giving home-based care, running support groups, and providing educational support for children.

**Participants:**
Doreen Mokoena
Salome Ragkwale
Kedibone Nkabinde

**Ekupholeni Mental Health Centre** in Katlehong, is a comprehensive, community-centred mental health organization. In the context of the HIV/AIDS pandemic, Ekupholeni is focusing on the complex interplay among mental health, HIV/AIDS and poverty, and criminal and gender violence.

**Participants:**
Mapotso Catherine Mphuthi
Maclarka Jeanet Rakhiba
Anna Gladys Masinga

**The GoGo Grannies Outreach Project** in Alexandria Township is a support group of grandmothers who have buried their own children and are now caring for their grandchildren with only the most meagre of resources. The GoGos aim to improve the quality of grandmothers’ lives, and thus, the quality of the lives of the children for whom they are the caregivers.

**Participants:**
Rosina Letwaba
Lucia Mazibuko
Thandi Petronella Makhanya
Madgeline Ramakobo

**Grandmothers Against Poverty and AIDS (GAPA)** in Cape Town, South Africa offers grandmothers emotional support and counselling, educational workshops, handicraft training, income generation opportunities, financial assistance for orphans’ schooling, and referrals to other organizations.

**Participants:**
Alicia Mdaka
Nontlupeko Cynthia Banisi
Mandisa Mafuya

**Hillcrest AIDS Centre** in Hillcrest operates a holistic and integrated programme of care. Their counselling programme extends into their home-based care project. And the income generating project not only provides an income for those who can no longer work but enables home-based care volunteers to earn a small income.

**Participants:**
Princess Ntombenhle Mkhize
Cwengekile Nikiwe Myeni
Lindeni G. Mbotho
The St. Nicholas Children’s Hospice in Bloemfontein operates a specialized programme of palliative care for children dying of HIV/AIDS, or other progressive and incurable conditions. The Hospice also supports the family and/or guardians throughout the course of the illness and into the bereavement period.

Participants:
Rebecca Semppe
Rayna Motsalepule Ntlonze
Leah Motsalepule Shuping

Treatment Action Campaign (TAC) advocates strongly for treatment for people with HIV and for the reduction of new HIV infections. TAC’s efforts have resulted in many life-saving interventions, including the implementation of country-wide mother-to-child transmission prevention and anti-retroviral treatment programmes.

Participants:
Lulekwa Dlelapantsi
Zodwa Hilda Ndlovu
Darlina Vuyelwa Tyawana

Thembalethu in Mpumalanga is a home-based care project whose 75 home workers look after 1,800 orphans and oversee 115 households headed by children 16-18 years of age. The homecare workers train the patient’s family on homecare, enrol children in school, and locate suitable relatives who will provide some support on a regular basis.

Participants:
Bridgette Moyana
Maria Nkosi
Siphiwe Thabethe

SWAZILAND

Swaziland Positive Living for Life (SWAPOL) engages rural communities in discussions about HIV/AIDS; provides training and education on positive living, nutrition, legal matters and treatment; supports orphans and vulnerable children; trains home care providers; establishes income generating projects; and counsels individuals and bereaved families.

Participants:
Cebile Dlamini
Thulisile Dladla
Juliet Magagula

TANZANIA

MKUKI in Himo is a community-based organization rooted in a rural environment. Over the years, MKUKI has expanded its services to include prevention, education, and support for those infected and affected by HIV and AIDS, in particular, children.

Participants:
Linna Mlay
Eventha William Shayo
Antonio Ignas

Pastoral Activities and Services for People with AIDS, Dar es Salaam Archdiocese (PASADA) is a medical and social service agency that makes available medical, social, material, psychological, and spiritual support at no cost. It provides palliative and home-based care, offers Voluntary Counseling and HIV testing (VCT) and supports almost 1,000 orphan children.

Participants:
Charles Weja
Salome Ngonyani
Tatu Ally Ligalwike

UGANDA

Kitovu Mobile AIDS Home Care and Orphans Project (MAHCP) is located in areas that lack basic infrastructure. More than 750 community volunteers are engaged in home care for people living with HIV/AIDS, education for orphans and their caregivers, training for school dropouts in organic agriculture, and psychosocial sup-
port including counselling.

Participants:
Nakayiwa Maria Gorreth
Teopista Munyinza
Nassiwa Cotty
Rosemary Nakijoba

Nyaka AIDS Orphan School in Nyakagyezi provides free education to AIDS orphans and strengthens social connections between AIDS orphans and local families. The school tries to create a family atmosphere that imparts self-confidence and positive values along with a curriculum that includes psychosocial supports.

Participants:
Twesigyi Jackson Kaguri
Christine Kasiime Turyasingura
Leonarda Ndazororera
Freda Byaburakiri

Reach Out Mbuya in Kampala provides medical care (including anti-retroviral therapy), and social, spiritual, physical, and emotional support to poor people in Mbuya Parish affected by HIV/AIDS. The majority of Reach Out’s clients are women, over half of whom are widows, many with a minimum of two dependents.

Participants:
Nkurunziza Ntale Joseph
Karmela Kasule Acen
Esther Wamala Nabachwa

St. Francis Health Care Services in Jinja cares for 5,500 patients and carries out far-reaching prevention activities. St. Francis also offers Voluntary Counselling and Testing and the treatment of opportunistic infections. In addition, the organization operates a community-based outreach programme to support People Living with HIV/AIDS and orphans.

Participants:
Faustine Victor Ngarambe
Sylvia Mubiru
Maria Theresa Kafuko

TII KI KOMI Women’s Group was started in Gulu by a small group of women (mainly widows with orphans) who grew cotton and other cash crops as a way of increasing household income on their own. When the insurgency began, the entire village was uprooted to a displaced persons’ camp but the group and its income-generating activities continue. To date, the group is composed of over 80 women of whom 75% are grandmothers.

Participants:
Komakech Julius Peter
Akelo Santina
Balbina Akidi Okot

ZAMBIA

Children in Distress (CINDI) in Kitwe provides care and support for children orphaned as a result of HIV/AIDS. CINDI identifies the children’s needs, acts as their advocate with the local authorities and society, and encourages communities to look after their orphans so that they grow up in a safe and caring environment.

Participants:
Janet Chisembele
Maggie Njobvu
Agnes Libala

PALS — Kara Counselling in Kabwe was founded by Winstone Zulu in 1991, just months after he was diagnosed with HIV. PALS fights stigma and discrimination by encouraging people living with HIV to talk about their status in the workplace, schools, churches, and market. PALS also started Ranchod Hospice and its Children’s Centre.

Participants:
Cherry Matimuna
Matilda Mwenda
Priscilla Mwanza
Umoyo Training Centre — Kara
Counselling in Lusaka operates a residential programme for young, orphaned women between the ages of 14 to 18. Umoyo provides skills for income generation, literacy and numeracy, and HIV/AIDS awareness. In addition, the girls develop self confidence, self reliance and ethical training — all of which is critical in assisting them to cope with difficult social and economic circumstances.

Participants:
Mwamba Mutale
Joyce Tembo
Elizabeth Mwewa

ZIMBABWE

Chiedza Child Care Centre (CCCC) in Harare strengthens the ability of grandmothers to cope with children in difficult circumstances, provides them with direct psychosocial support, and trains them in how to deal with bereavement. In addition, they help them develop a community-based model of orphan care and provide children with meals, school fees and medical assistance.

Participants:
Stella Purity Mesikano
Dorcas Kindon
Edith Miga Mlangali
Canadian Participants

The following is a list of grandmothers and groups that attended the Gathering from across Canada. Since August 2006, many new groups have formed or existing groups have changed their names. For an updated list of grandmothers’ groups, please visit our website.

**ALBERTA**

**Group:**
The GANG (Edmonton)

**Participants:**
Liz Roulston
Marion Rosborough
Maureen Ebel
Rosalind (Roz) Shepherd
Vicki Strang

**BRITISH COLUMBIA**

**Groups:**
Building Pathways with Grandmothers (Victoria)
CANDO Grannies (Squamish)
Can Go Grannies (Kamloops)
G. Van Go Grannies (Greater Vancouver Area)
GOGO Island Grannies (Victoria)
Grans to Grans (Nelson)
Nan Go Grannies (Nanaimo)
Grandmothers Enabling Grandmothers (Sidney)
Victoria Grandmothers (Victoria)

**Participants:**
Anne Pearson
Barbara Clay
Beth Gessinger
Beverley (Bev) Mill
Carol Judd
Carol Ward-Hall
Carolyn Neighbor
Comfort Ero
Cynthia Quinn-Young
Diane Morrow
Donna Anthony
Eva-Marie Marchioro
Jacquie Trafford
Jesse Pringle

**MANITOBA**

**Group:**
Gogo Action Winnipeg (Winnipeg)

**Participants:**
Claire Painchaud
Enid Butler
Marilyn Lombard

**ONTARIO**

**Groups:**
1st Unitarian Congregation of Ottawa Grannies (Ottawa)
Bridging the Gaps (Sudbury)
Burlington Ubuntu Grannies (Burlington)
Capital Grannies for Grannies (Ottawa)
Fergus Group (Fergus, Elora)
FOCUS (Feminists of Clarington United Sisters, Clarington)
Grammas & Such (Ottawa)
Grandmothers Alive (St. Mary’s)
Grandmothers’ Club of Mississauga (Mississauga)
Grandmothers’ Connection (Mississauga)
Grandmother Connection (Kingston)
Grandmothers Embrace (Alliston)

Joan Leitch
Laurie Drummond
Marilyn McVicar
Patt McGuire
Ruth James
Shelby Titian
Shelley Cairo
Sherry Goodwyn
Wendy Hamblin
Ycha Gil
Grannies and Wannabes (Toronto)
Grannies for Mbuyas (Prince Edward County)
Grannies United (Toronto)
Guelph GoGo Grannies (4Gs) (Guelph)
Hamilton Group (Hamilton)
London Grands (London)
Newmarket Granny's Village (Newmarket)
No To Go Go (Toronto)
Older Women's Network (OWN) (Toronto)
oomama (Niagara/Oakville/Grimsby)
Peterborough Grannies (Peterborough)
To Go Go Grannies (Toronto)
Women Who Sing (Burlington)

Participants:
Adelene Hyman
Alana Morgan
Ann McCallum
Anne Howells
Anne Philpot
Anne Richards
Anne Wisniewski
Beatrice Magder
Betsie Vant Spyker
Bev LeFrancois
Beverley Dales
Beverly Gardener
Bluma Teram
Bridget Hough
Carolyn Buchanan
Carol Macey
Carole Holmes
Carolyn Nixon
Cecilia Dronzek
Cinda Richardson
Deborah Stewart
Debra Jackson
Diana Ali
Diane Johnson
Diane Piasian
Dianne Gibson
Dinnah Mrango Lewis
Donna-Jean Brown
Elizabeth Kiddle
Elizabeth Rose
Elize Hartley
Ellyn Peirson
Flo Baron
Frances Bauer
Gail Orpen
Gemma Neal
Gessica Bell
Giselle Lalonde Mansfield
Heather Sole
Helen Ryan
Ione Grover
Iranee Zarb
Irene Podgorski
Jane Kelland-Germain
Janet Lewis
Joan Bailie
Joan Maloney
Joanne Hawman
Jo-Anne Page
Josephine (Jo) Casey
Judy Wayne
Julie Ashdown
Katherine (Sue) Bryant
Leslie Reinhart
Linda Sadiq
Linda Taberner
Loretta McDonald
Lorraine Reed
Lynn Bervaldi
Maggie Gibson
Margaret Motz
Margaret Smallwood
Maria-Ines Arratia
Marie Marsellus
Marion Abell
Marion Reid
Marsha Slivka
Marty Morgan
Mary Abernethy
Mary Easton
Mary Partridge
Mary Anna Beer
Mary Helen Garvin
Mary-Sharon Kennedy
Maxine Crook
Melanie McArthur
Michele Landsberg
Muriel Krizanc
Nancy Martin
Neil Blazevic
Noni Regan
Norine Baron
Olga Kolisnyk
Pamela (Pam) Churchill
Patricia Howe
Patricia Moffat
Patti Koeslag
Peggy Edwards
Penny Pattison
Philippa Schmiegelow
Reina Estrada
Rheta Thomas
Rosabelle Boateng
Rose Powell
Rosemary Munro
Rosemary Scott
Ruth Mechanicus
Ruth Smith
Sandra Street
Sharon Abbey
Sharon Polanski
Sharon Swanson
Shelley Porteous
Sherry Ardell
Shirley Farlinger
Sue Griggs
Susan Fletcher
Susan Robertson
Susan Savage
Thelma McGillvray
Theresa (Terry) Glover
Valerie Andrew
Valerie Antoniandes
Violet Rosengarten
Vivien Taylor
Wilma McCagg

QUEBEC

Groups:
Wakefield Grannies (Wakefield)
Chateauguay Grandmothers (Chateauguay)

Participants:
Anne Usher
Brenda Rooney
Carol Faulkner
Carol Pritchard
Cordula Podehl
Janet (Jan) McConnell
Marilee Rhody
Micheline Sabourin
Norma Peggie
SASKATCHEWAN

Group:
Grandmothers 4 Grandmothers (Saskatoon)

Participants:
Colleen MacBean
Dianne Van Hesteren
Judy Junor
Mary Pyne
Pat Grayston

USA

Group:
Concordia Grannies (Rhode Island)

Participant:
Susan Barr
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**GAPA Research**

A study to determine the effectiveness of the non-profit organisation, “Grandmothers Against Poverty and AIDS,” as an agent in the fight against the effects of AIDS on households headed by grandmothers.

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**BACKGROUND**

Arising out of and based on, a pilot intervention project of the Albertina and Walter Sisulu Institute of Ageing in Africa, a non profit organisation called Grandmothers Against Poverty and AIDS (GAPA) was formed (Ferreira and Brodrick 2001).

GAPA has been operating in Khayelitsha since October 2001. In that time the number of grandmothers participating in GAPA activities, namely workshops and psychosocial support groups has been steadily growing. Anecdotal evidence suggests that the grandmothers are developing the capacity to cope with the effects of the AIDS crisis and are becoming empowered members of their communities.

The intervention strategy of GAPA is a two pronged approach. Firstly grandmothers are invited to attend a workshop series which cover topics such as AIDS education, home care, nutrition, elder abuse, human rights, food gardening, drawing up wills, accessing social grants and business skills. These workshops are for a maximum of 30 grandmothers and are held over three days each month. The workshop facilitators are local experts in their field and some are grandmothers who have been trained by GAPA. All workshops are conducted in the local language, isiXhosa. Since May 2002, 250 grandmothers have attended a series of workshops at some time. The number of grandmothers attending continues to grow by 30 each month.

The second approach has been to invite grandmothers who are directly affected by HIV/AIDS in their families, to become members of a support group in their neighbourhood. The support groups consisting of between five and ten members are activity based. The groups are held in group leaders’ homes once a week. Education, problem solving and handicraft manufacture is carried out in the groups. The groups form autonomous units under the guidance and leadership of the group leader.

Home groups, as a support strategy were started in July 2002 to accommodate the growing number of grandmothers who wanted to join the existing psychosocial support group. Grandmothers who had been trained in the pilot intervention phase held between August and November 2001, had developed sufficient confidence in their own knowledge about HIV/AIDS and handicraft skills to lead others. An added benefit of the home groups was the eradication of the problem of transport costs incurred by grandmothers getting to the venue. Setting up groups in their neighbourhoods meant that grandmothers could now walk a short distance to attend their group. The logistical problems of feeding a growing and fluctuating number of attendees were also removed with the formation of home groups. The group leaders were given a cash allowance to provide food for the groups from their kitchens.
In July 2002 there were 3 groups. This grew to 6 by August 2002 and to 9 by February 2003. In July 2003 there were 12 groups. Monitoring of the groups began in earnest in July 2003 with the employment of a project manager.

Continuous monitoring of the groups led to the eradication of fictitious attendance books and the dissolution of one group. With the improved system, new groups were formed in new areas and some new group leaders were brought on board. In February 2004 there were 13 groups led by 8 group leaders. In December 2004 there were 19 groups held in 6 suburbs of Khayelitsha and run by 13 group leaders. Three groups were formed in the Eastern Cape in November 2003.

**THE STUDY**

In order to evaluate the effectiveness of GAPa’s presence as an agent in the fight against poverty and AIDS amongst grandmother headed households in Khayelitsha, a qualitative and quantitative study was conducted from July 2004 to December 2004.

**Children who cohabit with grandmothers**

One hundred and fifty five respondents reported that 515 children under the age of 21 years lived in their homes. Of these 366 were grandchildren. The other 149 children were either their own children, foster children or children of close relatives that they were responsible for.

**Benefits received due to GAPa membership**

In response to the item “Have you made any money for yourself from being a member of GAPa” 65% of respondents said that they had made some money. Responses were vague ranging from, “a little” to “a lot.” In less than 23% of cases an actual monetary value was given. Two respondents were definite that they made R100 per month and R25 per month. The range was from R10 to R2000. Others who gave a monetary value did not specify over what time period they had made the money.

Sixty four per cent of grandmothers reported that they had benefited from being a member of GAPa by receiving school fees (81%) and food (57%). Four respondents said that they had received materials with which to do handicraft. However all grandmothers receive fabric and other handicraft materials in their groups as well as a meal.

**What grandmothers had learned as members of GAPa**

All participants reported that they had learned something from being involved with GAPa. The responses fell into the following categories:
- Acceptance - “To be able to help a person with HIV and to teach others how to accept them”
- Home nursing - “You can support the HIV+ person without becoming sick”
- Practical skills - “How to grow vegetables and how to sew”
- Income generation - “How to make extra income”
- Peer support - “Cooperation and love brings success”
What was the best thing about being in a group

Participants’ responses fell into the following categories:
Stress alleviation – “We have a chance to relieve stress”
Income generation – “Financial security because of the sewing”
Companionship – “Not sitting at home being unhappy and alone”
Safety – “You feel free to communicate your feelings to other people”
Problem solving – “Problems are shared about HIV/AIDS”

What was the worst thing about being in a group?

Ninety percent of the respondents said that there was nothing negative that could be said about being in a group. Those that did report something negative generally complained about arguments within the group and in two cases about the unfair distribution of goods within the group.

Community intervention by grandmothers

The responses to the item “How can you help people who have HIV/AIDS in their families” fell into the following categories:
Referral – “By referring them to the nearest group of GAPA”
Tolerance – “By asking them to accept the child so that he/she can accept the disease”
Education – “To teach them how to look after people who have AIDS and not just to throw them away”
De-stigmatisation – “Teach them not to hide it, look after herself honestly. This is not the end of the world”
Practical help – “I can help the person to bath the HIV+ person, I can cook for them and comfort them”
Counselling – “Counselling, giving hope, its not the end of the world to be HIV+”

THE MONTHLY INDABAS

Every month from July 2004 to December 2004 all members of GAPA were invited to attend an indaba at the GAPA centre in Khayelitsha. The average monthly attendance was 90 grandmothers. The programme of the gathering followed a similar format each month. It included a talk about HIV/AIDS by one of the group leaders, prayer and song and an hour where grandmothers were invited to address the group about what belonging to GAPA meant to them. By giving them an open topic to talk about the researchers discovered what the grandmothers felt to be most important issues in their relationship with GAPA. Their testimony was recorded and transcribed from isiXhosa into English for later analysis. The testimony by individual grandmothers caused the atmosphere of the gathering to be emotionally charged and there were frequent outbursts of crying and wailing by grandmothers who were overcome by emotion. After each grandmother’s testimony there would a short spiritual song or a prayer by the whole group. These sessions were therapeutic for the individual speaking out as well as for others who could relate to their stories.
The data gathered were rich and multitudinous. The researchers sorted the data into broad categories based on issues that the grandmothers repeatedly brought up when they were addressing those present at the indabas. Their testimony dealt with subjects such as their health and their interactions between their families and their communities. Direct quotes from what the grandmothers said at the indabas, capture the essence of what they consid-
ered to be the most important issues surrounding the AIDS epidemic and their interaction with GAPA.

**Grandmother’s health**

Many of the grandmothers said that being left on their own to cope with death and illness in the family caused them to suffer from stress and ill health.

“Before I heard that my daughter was HIV+ I had nothing wrong with my health. No high blood pressure, no diabetes, but when she fell sick with TB and I was told it was HIV, I was devastated, I became sick myself. When I met the people who were attending the GAPA group I felt better. Even when she died leaving a 5 year old baby I was stronger than before.”

**Family dynamics**

Grandmothers spoke of being isolated from their communities because of the stigma associated with the unknown. In some cases grandmothers revealed that their family members had kept their conditions secret and denied being infected even though they were very ill.

The value of being in a support group was described as providing education about the disease and providing emotional support which gave them strength to speak openly about AIDS.

“It is good to talk about HIV to protect it from being a scary thing.”

“Our lives have been touched by GAPA. It taught us to accept HIV as other diseases. I am staying at home with my daughter who is HIV+ but sometimes forget she has that disease. That is the way GAPA made me accept HIV. I am at peace with the disease.”

Grandmothers who received preschool fees for their grandchildren expressed relief that children who otherwise would be kept at home had somewhere safe to go to during the day.

“We have grandchildren with whom we were sitting alone at home. I am no longer with sorrows because my grand daughter is at preschool paid for by GAPA.”

“Now my grandson attends a preschool and is paid for by GAPA because I don’t have any money to pay for him.”

**Interaction with others in the group**

Some grandmothers described how when a GAPA group leader invited them to join a support group in their area they went along to the group with scepticism. However they soon realised the benefits of the knowledge, understanding and emotional support they received from their peers. Joining the psychosocial groups gave them a feeling of togetherness and acceptance with others in their group.

“When I entered Mrs M’s house (group leader) I could feel the acceptance in the women that she was working (sewing) with. Now even if people talk about AIDS I no longer get anxious thinking that they mean the AIDS in my family. I have learned to accept all situations and sicknesses through GAPA”

Furthermore they learned new practical skills such as sewing and gardening. They were very proud of discovering that they were able to make useful household articles that they could sell or use in their own homes. Planting their own vegetables was also a source of pride to them.

“I gained a lot from GAPA. I now eat vegetables, cabbage and spinach grown in my garden.”
CONCLUSION

Results of this research project are very encouraging and show conclusively that GAPA is making a positive contribution to the lives of grandmothers and their families. The information that grandmothers receive in workshops, from group leaders and their peers equips them with some practical skills to cope with their daily lives. Food gardens have been started in homes, financial aid in the form of government grants has been accessed, handicraft groups have been started to increase household income and small children have been sent to preschool.

Grandmothers have found strength in one another to speak out about the stigma that existed around families that had HIV+ members and to lean on each other in times of family deaths and crises. GAPA has bred a group of grandmothers who are well informed and concerned for their families and communities in an atmosphere of ignorance and fear of HIV/AIDS. Grandmothers indicated time and again that with each others support they were willing to share knowledge with their communities. Furthermore they acknowledged that a problem shared became less of a problem and resolved to encourage families to disclose their HIV status so that they too could benefit from community support.

To sum up, HIV/AIDS is killing the younger people in South Africa and it is the grandparents who will be left with the burden of bringing up future generations of South Africans. The problem has been succinctly put by a grandmother at an indaba;

“Elderly women are crying on their own with no one to talk to. It has turned from them expecting to be buried by their children, now elderly women bury their children. That is not nice, we need to comfort each other under this umbrella (GAPA).”
Grandmothers to Grandmothers Campaign

GRANDMOTHERS: THE UNSUNG HEROES OF AFRICA

Africa has become a continent of orphans — an estimated 13 million children have been orphaned by AIDS in sub-Saharan Africa and the numbers are expected to reach 20 million in the next four years. In the midst of this devastation, grandmothers have emerged as the ‘unsung heroes’ of Africa. They bury their own children and then in their 50s, 60s and 70s begin to parent again, raising their grandchildren with little to no support. In some countries, 40-60% of orphans live in grandmother-headed households. These courageous and resilient women have no time to grieve. Their priority is the next generation: the infants, toddlers, and teenagers who are left behind. Although there is never enough for their burgeoning households, somehow these grandmothers attempt to feed, clothe and comfort their grandchildren.

LAUNCHING THE CAMPAIGN

Toward the end of 2005, Stephen Lewis and his daughter Ilana Landsberg-Lewis began discussions about how to support grandmothers in Africa. During his travels in Africa, Stephen heard first-hand from grandmothers about the challenges they face in raising their orphaned grandchildren. At the same time, Ilana was reading countless proposals and recognized that grandmothers were increasingly fundamental to programmes working on AIDS at the grassroots. While SLF was already supporting women, orphans and organizations of people living with HIV and AIDS, it became clear that a fourth area had to be added to the mandate: support for grandmothers.

In March 2006, on the eve of International Women’s Day, the Foundation launched the Grandmothers to Grandmothers Campaign, which was designed to raise awareness in Canada about the plight of Africa’s grandmothers and to mobilize support. At the time of the campaign launch, there were six groups of Canadian grandmothers who had chosen to fundraise and send proceeds to SLF to help support their peers in Africa. By the time of the August Grandmothers’ Gathering, 50 Canadian grandmothers groups had formed. It can truly be said that the grandmothers have taken up the cause and have mobilized a movement that is over 140 groups strong!

SUPPORTING AFRICA’S GRANDMOTHERS

The Stephen Lewis Foundation funds grassroots organizations that assist grandmothers caring for AIDS orphans in 14 African countries. The Foundation provides grandmothers with much-needed assistance, including: food, school fees and school uniforms for their grandchildren, income-generating projects, counselling and social support, and coffins to allow for a dignified burial of their loved ones.
The Stephen Lewis Foundation (SLF) helps to ease the pain of HIV/AIDS in Africa by funding community-level projects that provide care and support to women, orphans, grandmothers and associations of people living with HIV and AIDS (PLWHAs).

www.stephenlewisfoundation.org