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African Grandmothers TRIBUNAL

Seeking justice at the frontlines of the AIDS crisis

Tribunal Report

September 7, 2013
The Chan Centre at UBC
Vancouver, British Columbia
Canada

the Stephen Lewis
FOUNDATION

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Preface

The “People’s Tribunal” was an astonishing exploration of the way in which African grandmothers contend—both poignantly and courageously—with their beleaguered lives. It was, of course, a logical extension to the Grandmothers’ Gatherings in both Canada and Africa, as well as the frequent trips, back and forth, of African grandmothers to Canada and Canadian grandmothers to Africa. It’s no exaggeration to say that an international Grandmothers’ movement has been created.

We don’t pretend that this is some supernatural achievement on the part of the Foundation. But we would argue that recognition of the struggles of grandmothers, and their collective embrace of orphans, is unique in the annals of the HIV and AIDS pandemic. What’s more it’s indispensable. Let us explain why.

The current mantra in dealing with AIDS is “zero deaths,” “zero new infections.” It’s a strategy promoted by UNAIDS with the support of the scientific and political establishments. And it’s entirely admirable except for one fatal flaw: it leaves out whole categories of people who are adversely affected by the virus. Two of those categories are grandmothers and orphans.

Incredibly enough, in the latest issue of the comprehensive UNAIDS update on the pandemic, 2013, published just a few weeks ago, grandmothers and orphans are written out of the text. They nowhere appear!

Where grandmothers are concerned, this could be seen as a willful slap to the face of gender equality; where orphans are concerned, it could be seen as a gross violation of the Convention on the Rights of the Child. Taken together it’s an astonishing gap in the response. But ours is not to take issue… ours is to demonstrate why the Tribunal was so profoundly important.

Somewhere, some organization—and in this case, we proudly say it’s the Foundation—must give profile to the grandmothers of Africa and the staggering demands they face in raising orphan grandchildren. In several countries, the grandmothers, many who are themselves HIV-positive, look after between 40 and 60 per cent of the orphans, and there are some 15 to 16 million orphans.

In the face of this intense human predicament, we could become insensate with rage at the injustice of it all. But that’s not our choice. Our choice is to honour the grandmothers, enfold the orphans in our arms, and support them to make all of their lives whole again.

Stephen Lewis
Chair of the Board & Co-Founder
Stephen Lewis Foundation

Ilana Landsberg-Lewis
Executive Director & Co-Founder
Stephen Lewis Foundation

Introduction

African grandmothers are saving their communities from the worst ravages of the HIV and AIDS pandemic. They have stepped in to care for orphaned grandchildren, putting them through school, supporting them through the loss of their parents to AIDS, and teaching them about HIV prevention and treatment. They tend to the sick, set up support groups, harvest the crops and create income-generating programmes. They are advocates for their families, and are emerging as experts and leaders, increasingly acknowledged by governments and international organizations.

But discrimination and gender inequality are making them pay an unconscionable price. Grandmothers are subjected to violence in their homes and from their family members. Wife inheritance and other harmful customary practices endanger many grandmothers, and expose them to a high risk of HIV infection. Grandmothers face a triple threat of discrimination, based on sex, age, and HIV status, and their access to healthcare is often extremely limited. The death of family members has destroyed their previous economic support systems, while at the same time greatly expanding their responsibilities for the care of orphans and vulnerable children and other members of their communities. As well, property grabbing is a constant threat to grandmothers' housing security, and to their ability to hold on to the land they need to feed their families.

African grandmothers deserve better—they deserve justice. On September 7th, 2013, in Vancouver, British Columbia, Canada, the Stephen Lewis Foundation hosted a People's Tribunal to shine a public light on the denial of their human rights, and to issue a call for action. Grandmothers from across sub-Saharan Africa presented their personal testimonies, and leaders of community-based organizations shared their expertise about some of the most pressing human rights challenges grandmothers are facing. In response, the Tribunal's judges spoke powerfully and with great urgency about the remedies that must now be delivered. The Tribunal concluded with the voices of the courageous African grandmothers, who sent out a clarion call for change: the time has come for their rights to be promoted, protected, and respected.

The Tribunal marks a shift and an important turning point in the Foundation's work with African grandmothers, and the organizations run by and for them. Much has led to this transformational moment, and it reflects the tremendous strides that have been made by grandmothers and community-based organizations on the continent.

The HIV and AIDS pandemic brought utter devastation to sub-Saharan Africa in the 1990s and early 2000s. There were no drugs available anywhere and none on the horizon. People were dying in massive numbers. Young people in their most productive years, those in their 20s, 30s and 40s were dying at an astounding rate. What this meant in the life of communities was an enormous proliferation of grandmother-headed households, households filled with traumatized orphaned children.

This led the Foundation to host the Grandmothers' Gathering in 2006, immediately preceding the XVI International AIDS Conference in Toronto. The Foundation brought 100 grandmothers and staff from community organizations in sub-Saharan Africa, together with 200 Canadian grandmothers, for three days of dialogue and workshops. At that time, the conversation was entirely absorbed with the ravages that AIDS had wreaked on the grandmothers' families and communities. It was all about grief, and overcoming grief, fear and stigma, parenting traumatized children, and isolation. It was about the desperate search for resources to support their families, and the huge shift they were trying to make in their lives to become breadwinners and parents again.

Canadian grandmothers responded with breathtaking speed following the Gathering, forming more than 200 groups across the country. Between 2006 and 2013, the Grandmothers' Movement went on to engage in a host of awareness-raising and fund-raising initiatives, generating more than $19 million dollars. These funds were sent directly to the grassroots organizations run by and for the African grandmothers and the orphans in their care.

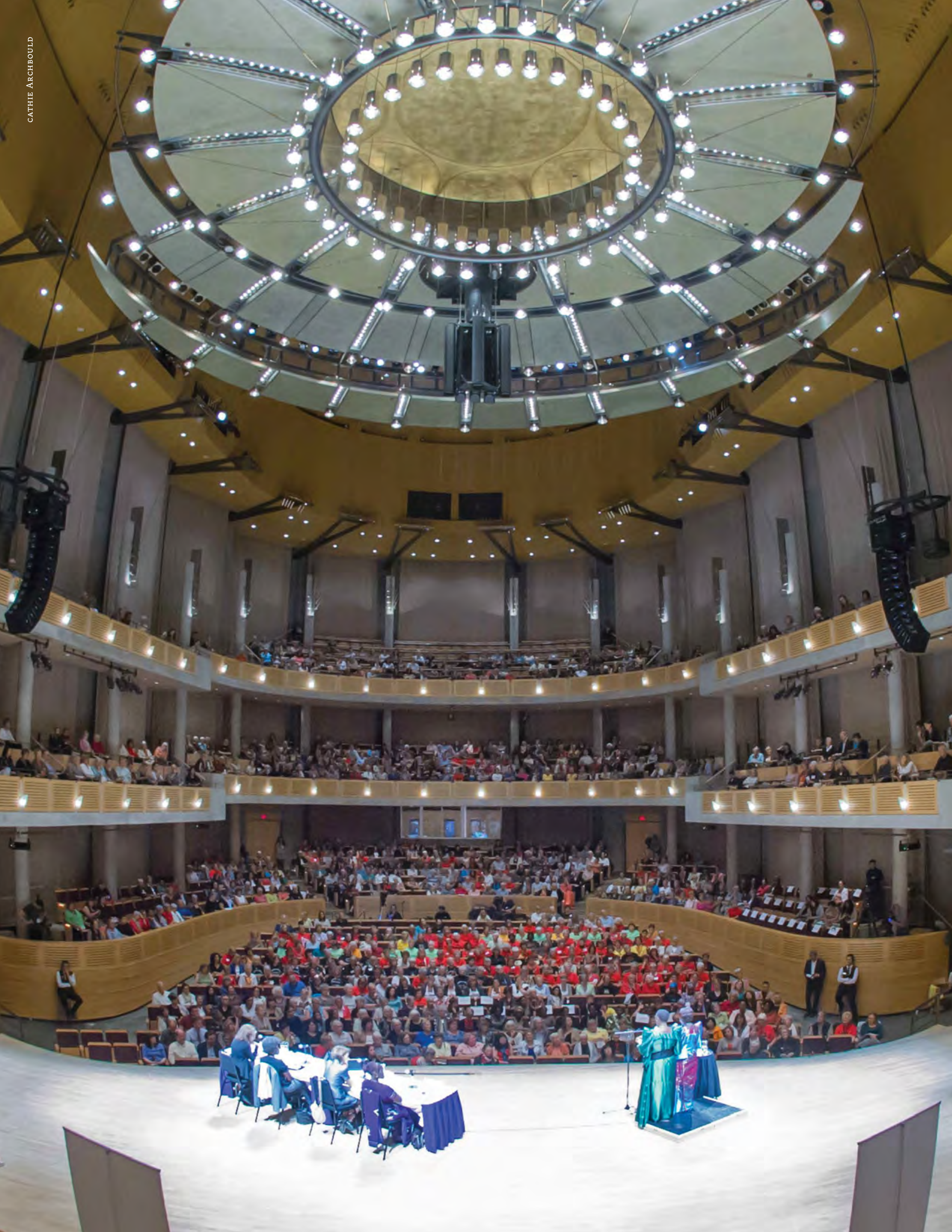
In 2010, the Foundation approached one of our flagship partners, Swaziland Positive Living, to co-host an all-African Grandmothers' Gathering. It became clear at the Manzini meeting in Swaziland that a remarkable transformation was taking place because of the support that had been flowing to the grandmothers and their organizations. The grandmothers who were supported by the Foundation's partner organizations now had the modicum of resources that allowed them to create some basic, immediate security for their families. With their own burdens lightened, they were starting to grapple with the larger challenges that were hindering their ability to ensure a better future for themselves and their grandchildren. They were also possessed by concern for all of the other grandmothers who were still struggling, beyond the reach of their organizations. In Manzini, the discussion was about the broader changes needed to improve their access to healthcare, to ensure children could stay in school, to prevent violence and land grabbing, and to secure adequate pensions. At the meeting's conclusion, the African grandmothers articulated a platform of action for systemic change and international support.

A People's Tribunal seemed the obvious next step for the Foundation. The Tribunal provided a prominent, public forum for the grandmothers and their organizations to make their claims. The grandmothers gave powerful testimony that illuminates the human rights violations they've been experiencing. And the judges, in their statements, established that the changes they are demanding are required as a matter of justice, not of benevolence or charity. The grandmothers must no longer be left to struggle alone for the survival of their communities. It is the human rights obligation—of their governments, the international community and donors—to ensure their protection from violence, dispossession and extreme poverty, to provide adequate healthcare, to ensure food and housing security, to guarantee the children's education, and to empower the grandmothers to take a leading role in the development of policies and programmes to turn the tide of AIDS in Africa.

As the grandmothers themselves concluded in their Call to Action:

> *"It is time to recognize that grandmothers at the forefront of the HIV and AIDS crisis must have our human rights respected and protected. We will not let the AIDS pandemic defeat us nor destroy our communities, but we cannot prevail alone. Africa cannot survive without us. We call on you to act with urgency and purpose to support our efforts to secure justice."*

CATHIE ARCHBOULD



Summary of Tribunal Recommendations

Four distinguished women served as judges on the Tribunal, hearing the grandmothers' and experts' testimonies and issuing their decisions: Theo Sowa, Chief Executive Officer of the African Women's Development Fund; Mary Ellen Turpel-Lafond, British Columbia's Representative for Children and Youth; Joy Phumaphi, Executive Secretary of the African Leaders Malaria Alliance, and Gloria Steinem, renowned feminist author and activist.

Income Security

The grandmothers are suffering from an extreme depletion of their resources, in every sense—economic, emotional, physical and spiritual—because of the challenges they face in the struggle to support families devastated by HIV and AIDS. After the death of so many parents, the grandmothers stepped in to care for the orphaned children regardless of what the limits of their own personal strength and resources might be. They have been emptying their small savings, begging, farming small plots of land while holding off property grabbers, studying new skills to earn bits of income, exhausting themselves with piece work and day labour, and loaning any money they have to each other through table banking. Local grassroots NGOs have done whatever they can, whenever they can, with their limited funds, providing bedding and foodstuffs, seeds and fertilizer, repairing homes, and paying for school fees, uniforms and books. It's rarely enough. These families are living precarious lives, under the constant threat of extreme poverty. One bad financial turn can lead to hunger, the end of the children's schooling, inability to access HIV treatment, or homelessness.

Grandmothers' human rights are being doubly violated. First, because they themselves are not protected as they should be from extreme poverty, hunger and homelessness. But second, and more insidiously, because they have been left to meet the burden of the State's proper responsibilities for the children and vulnerable people in their communities though their own unpaid labour.

To protect grandmothers' right to income security, the judges have recommended:

- Granting pensions or cash transfers to grandmothers, at a level that is sufficient to cover both their needs and the needs of the children in their care
- Expanding the economic opportunities available to grandmothers
- Compensating grandmothers for their work as community caregivers
- Eliminating school fees, and all ancillary costs, for primary and secondary schooling

Housing, Land, and Property

Having well-built, secure shelter, with land nearby that can be farmed for crops to eat and for sale, is what has made it possible for so many grandmothers to support themselves and their grandchildren. But the pandemic has brought a crisis of mass eviction into grandmothers' lives. In cultures where men are the traditional owners of land and property, grandmothers become dangerously vulnerable when their husbands die due to AIDS, or when they are faced with divorce or abandonment. The stories that Immaculate and Magret have shared with us, about their relatives' campaigns to grab their land and property, are not unique. They have been repeated in community after community, across the countries of sub-Saharan Africa, and reflect a pernicious intersection of HIV and discrimination against women.

The challenge that grandmothers are confronting is not simply that they have no legal rights—often it is that these rights are not being recognized and enforced in their communities. Many grandmothers are not able to afford the high cost of bringing a legal claim. They also face justice systems that favour people with money, all the while enduring harassment from their in-laws and struggling with the day-to-day burden of the disease and care for their grandchildren. Many are overwhelmed by this many-sided assault, and give up. But not all. As the grandmothers have told us in their testimony, support from grassroots NGOs, women's lawyers' associations, legal aid, responsive police officers and local officials, and gender-sensitive land tribunals—especially those that include grandmothers as decision makers—can make a tremendous difference.

To protect grandmothers' rights to housing, land and property, the judges have recommended:

- Reforming national constitutions, laws, and policies
- Making courts, policing, and legal aid more accessible and responsive to grandmothers' claims
- Supporting customary and religious legal systems to eliminate discriminatory practices
- Ensuring that local administrations respect grandmothers' equal rights in the division of marital property and inheritance
- Returning all land, housing and property that has been taken illegally
- Providing housing to grandmothers who have been left homeless

Healthcare

In recent years there has been a dramatic increase in the number of people receiving life-extending, life-saving antiretroviral (ARV) treatment for HIV and AIDS. Unfortunately, grandmothers are not the main beneficiaries of this change, and they continue to suffer from very limited access to healthcare. Sex-based and age-based discrimination continue to marginalize them within healthcare programmes. The obstacles and challenges they face are mainly ignored—their isolation, lack of information about the disease, inability to travel long distances, the high costs of drugs, and vulnerability to violence. As the global community is poised to intensify its efforts to deliver treatment for HIV and AIDS, we must insist on improved treatment for grandmothers as a priority.

To protect grandmothers' right to health, the judges have recommended:

- Including grandmothers as a target population in national plans to scale up access to HIV and AIDS treatment
- Developing community-level programmes to address the challenges older women face in accessing treatment
- Engaging grandmothers in the design and delivery of community-based care
- Eliminating all out-of-pocket costs for HIV and AIDS testing and treatment
- Prohibiting discrimination against people living with HIV and AIDS, and undertaking anti-stigma campaigns with strong support from prominent local and national leaders

Violence Against Women

Women living with HIV are more vulnerable to violence. According to a recent Zimbabwean study, the rates of reported sexual or physical violence are 20% higher among women living with HIV than other women. That's often because women are more likely than men to be blamed for bringing HIV into the family, and are much more likely to be battered as a result. Husbands become aggressive and violent towards the HIV-positive wives they want to drive from their homes, and the stigma of HIV and age make older women less willing to report the violence, especially sexual violence, that has been done to them. Perhaps hardest for a grandmother caring for AIDS orphans is reporting the violent behaviour of one of her troubled and traumatized grandchildren.

Poverty plays a role as well. Women who must travel long distances to find work, sell their goods, or reach hospitals and clinics for treatment are exposed to attack. Grandmothers who are desperate for money to support their families can be forced into dangerous working environments, such as truck stops, illicit brewing, and prostitution. Many grandmothers living in urban areas suffer from extreme isolation. The social networks of kin and community that still exist in rural areas have virtually disappeared in the cities, leaving them vulnerable and defenseless. Housing that is insecure and in bad shape encourages local men to enter uninvited, and take what they want by force. Relatives will destroy crops and property, and physically attack grandmothers and their family members, in attempts to scare them off their land.

To protect grandmothers' right to live lives free of violence, the judges have recommended:

- Enacting and enforcing laws to prohibit domestic violence, marital rape, and sexual violence
- Making courts, policing, and legal aid more accessible and responsive to grandmothers' claims
- Strengthening community-level mechanisms to prevent, investigate, and punish acts of violence
- Eliminating harmful traditional practices, such as wife inheritance
- Raising awareness at the community level about women's right to be free from violence

Grandmothers' Leadership

The grandmothers' testimonies revealed just how much they have been able to accomplish for their families and communities—drawing only on their own hearts and spirits, and the support of those grassroots NGOs who understand the importance of their role. Grandmothers are feeding whole neighbourhoods of children, and monitoring their health and well-being. Grandmothers are advocating for an end to discrimination and violence, encouraging women to claim their rights, and helping them get protection and redress. Grandmothers are helping to remove the stigma and ignorance that hold people back from treatment and testing, and giving the day-to-day support that keeps people in treatment. Grandmothers are advising on the boards of NGOs, and they are becoming part of local governance. Perhaps most significantly, grandmothers are joining together, forming mutual support groups and creating their own organizations to help advance their work. In short, grandmothers are showing the most inspirational type of leadership—and they deserve support to make that leadership count fully.

To advance grandmothers' leadership, the judges have recommended:

- Including grandmothers in all national and local bodies that make HIV and AIDS-related decisions

- Increasing grandmothers' representation in community-level bodies that make decisions on issues that affect them, such as local land committees
- Strengthening the community-based organizations that are facilitating grandmothers' advocacy and organizing

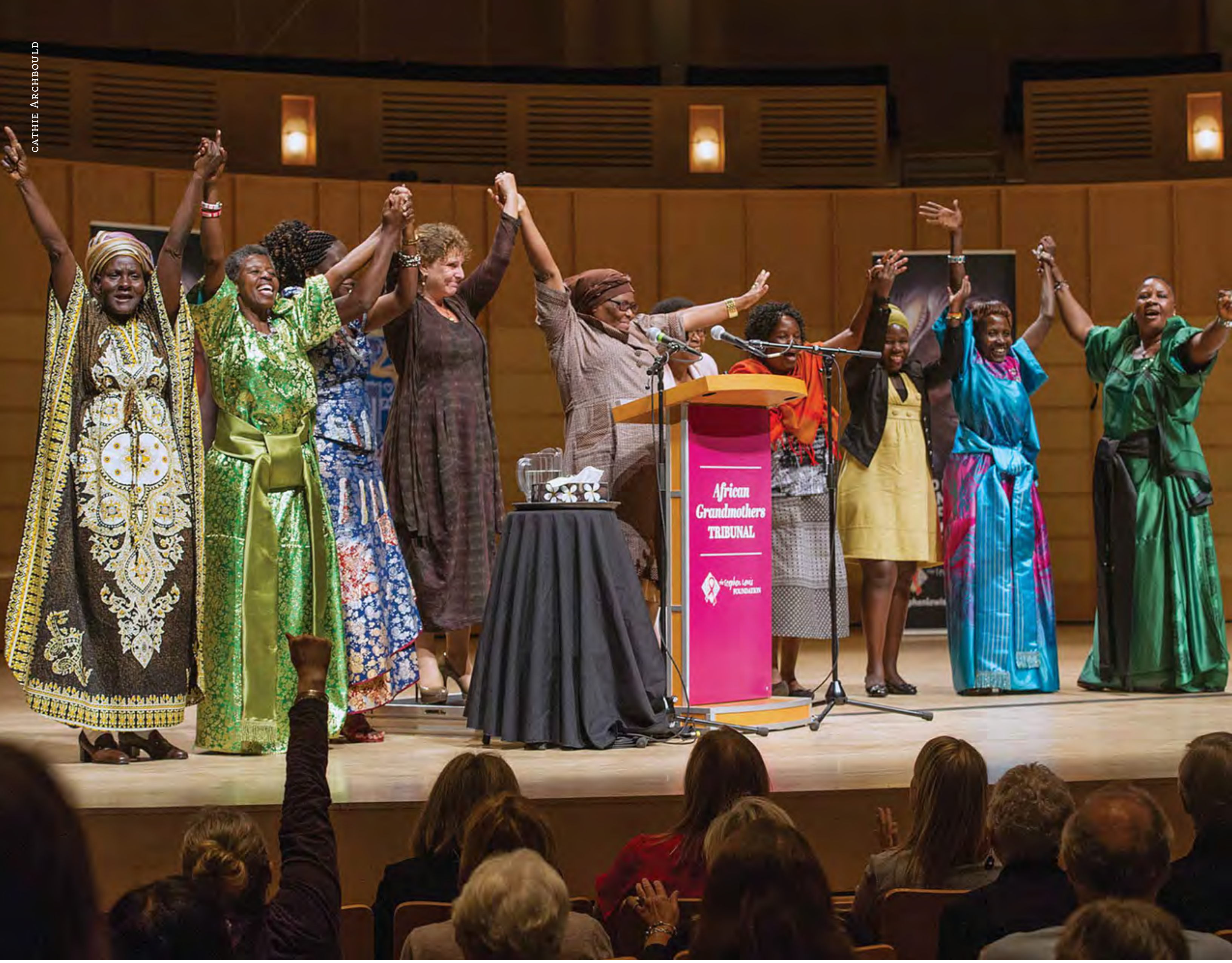
Financing for Grandmothers' Rights

Last year, UNAIDS estimated the amount of money being spent on HIV and AIDS-related initiatives that target women. The first shock: only 85 of the 127 countries who prepared progress reports on their HIV and AIDS spending indicated that any money was being allocated to programmes that specifically target women. The second, even greater shock is the utterly trivial scale of this funding: only US $288 million was reported worldwide last year for women-specific interventions. Of that sum only US $20 million was spent on HIV-related anti-violence interventions and other programming that directly addresses women's concerns.

The funding picture is just as troubling when it comes to the care and support work of local, grassroots NGOs. When we hear about funding for AIDS in Africa, the focus has always been on the provision of drugs. Of course, this is desperately important; only 50% of those who need antiretroviral drugs are receiving them, and only 25-29% of the children who need pediatric ARVs can access them. But drugs don't deliver themselves, and drugs alone won't heal the damage done by the pandemic. Much more support is needed for the community-based organizations that have become the backbone of the healthcare response to HIV and AIDS on the ground.

To improve the financing for grandmothers' rights, the judges have recommended:

- Allocating resources to implement all of the above measures
- Increasing the funding available to community-based organizations
- Establishing a multi-donor programme for sub-Saharan Africa, to fund cash transfers for grandmothers



Cathie Archbould

Grandmothers' Testimonies

Cathie Archbould

Thulisile Dladla

Manzini Region, Swaziland

I first heard of SWAPOL in 2001. They came to my community and started asking us why so many children were not going to school, and I told them there was no money. We started working with SWAPOL, and SWAPOL paid for the school fees and for their uniforms, and also for the hospital fees for the children who were HIV-positive. We joined the support group where people were told that being HIV-positive was not the end of the world, we were taught how to live positively as women with HIV in the community, and they also gave us ideas about how to generate some income.

There were so many children coming morning and afternoon to SWAPOL to take their pills. But I could see they were hungry, they weren't eating. So I talked to SWAPOL about the problem. I volunteered and said I have a rondavel that we can use, and I can stay with the children here in my house and feed them, there is no problem. We set up the Neighbourhood Care Programme in 2001 and we are still doing it, and we look after about 45 children. I take care of the children by cooking, making sure they go to school, and looking after their health.

This comes from my own experience. I grew up in a very poor family and nobody at that time was responsible for us. So I felt the need to do something for these kids, to protect them and care for them. That is actually what keeps me going. That is what motivates me. The feeding is actually a platform where I can screen all the kids, ask them why they are not going to school, check on the status of their parents if they are still here, and if I need to I will go to see if they are bedridden and what is happening.

We are also paying school fees for the children. For some of them, if it was not for SWAPOL coming here, they would not be in school. To see the change that now they can read, they can write, they can speak English, though their parents are dead, but they manage to access education—that is what I am enjoying. These are fruits, not for my own children, but for my grandchildren and all of the children.

It is very emotional to lose your family, and very painful, especially to HIV. It does not happen quickly.

My own life I am not enjoying just like any other woman. My husband died, and three of my children died. I found out that I am positive and I am on treatment. I am diabetic and also taking treatment for hypertension. Aging with HIV and AIDS is more difficult due to the increased treatment I must take and dealing with the various treatment complications alongside my role as a caregiver. And I cared for so many of my family members when they were dying of AIDS. It is very emotional to lose your family, and very painful, especially to HIV. It does not happen quickly. You are caring, you are caring, you are caring, and you keep on saying "Don't be afraid, you will be better." And then one day you check on them and they are dead. You lose the love you had together with your family, and instead of that love you have bad memories about the disease.

You lose the love you had together with your family, and instead of that love you have bad memories about the disease.

You also lose your family structure. When he was alive, my husband was working, but today sometimes I don't even have money to pay the electricity or put food on the table. I take care of six grandchildren on my own. Three of my four children died and I was the one left taking care of them. Fathers often run away in a crisis, they don't stay to take care of children. I have no savings of my own, and the only money I have comes from the income-generating activities SWAPOL supports. I get a small income to put food on the table, but it is still a struggle with my grandchildren's clothes and school fees.

It's the same for all of us grandmothers. At my age you don't have much energy to take care of people, but now I have to find the energy, because if I don't cook for these children no one will. I have to be working all the time caring for the children on every level. The people in our families who used to support us are all gone. I'm taking care of children all over again for a second time. But I find the energy from my inner strength because I believe in children, they are the future, and by helping them I am planting seeds for the future.

We are advocating now with the government, with SWAPOL's support, to change the way that grandmothers are being given grants. The grant is supposed to help grandmothers cover the many expenses they have when they are caring for grandchildren. But there's a problem with the law. Right now it says that you have to be at least 60 years old to receive a grant. The age must be changed to 45 or 50. Many women caring for orphans are much younger than 60 and the money comes too late. I am in my fifties now, and I have been caring for orphans already for many years, with no support from the government. I'll still have a long time to wait if the law isn't changed. This is a priority issue we are taking up this year. It is an election year, and we grandmothers are talking to our MPs, letting them know that if they want our votes, they must change the law.

We are not doing this because we like to lobby. HIV has robbed us of our key young people, who were working to support us. We lobby because of this situation we are in. We are old, and we are sick, but someone has to take responsibility for the orphans. By supporting the grandmothers you are supporting the orphans who are living with us. As a grandmother, I will make sure that before I sleep everyone has eaten, everyone has actually been taken care of. All of them.

Another big problem is high school. High school is too expensive, it costs 4,000 rand (about $400CDN) and upwards, just for school fees. The income-generating project I am in only provides about 500 rand a month – and I use it to put food on the table and meet our daily needs. Primary school just teaches the basics, but you can't get decent work just with primary school. High school equips you to make a decent living, and for the children to have good futures they must go there. Paying for high school is a huge challenge for us grandmothers. SWAPOL can only help with primary school. The government will help you sometimes if you meet certain conditions, but you need to show birth certificates and death certificates from both parents.

I was privileged the last three years to be elected as a member of the Sibovu Primary School Committee. I work to sensitize the committee about the plight of the orphans in acquiring these documents. I advocate with schools to be lenient with orphans about this requirement, since it is so hard for them to access birth certificates or death certificates of parents. Often if they exist, they are grabbed by family members to claim insurance or inheritance.

By supporting the grandmothers you are supporting the orphans who are living with us. As a grandmother, I will make sure that before I sleep everyone has eaten, everyone has actually been taken care of. All of them.

The government needs to start talking with us, with community caregivers, more, so that they know what the real problems are. Right now, what the government is doing is choosing who to pay for and who not to pay for, helping some children but not others. SWAPOL is advocating that they just eliminate all the individual fees that are creating such a problem for us. I'm doing a lot of my advocacy work now on education, because it's the most important thing for the children. It's the best protection we can give them for their futures, and to make sure that when we are gone, they will actually be able to take care of themselves.

Education is a huge challenge, and so is healthcare for these children. Especially for orphan children who are HIV-positive, school is not possible without free healthcare. SWAPOL has a mobile health clinic which provides children with the ARV treatment. They are screened, immunized, have growth monitoring, and are provided with the drugs for HIV right at community level. This means the children can easily walk to the SWAPOL treatment sites every month at no cost. Children are healthy because of the outreach programme.

Working with SWAPOL is really a blessing in my life, because the children are doing better now; some of them have managed to go up to university level, and some of them are working. They sometimes come here and buy me something just to show their appreciation that I took care of them. Even though we are not related, I have that passion for them, to see them being happy people even though their parents are not here.

Every year in December we come to SWAPOL and celebrate Christmas with the children. We sit together and the children are happy. You cannot tell that these are orphans because they've got me who is always thinking about them. For me, caring, it is my passion. SWAPOL used to have money to give us caregivers a monthly stipend, but they can't anymore, although maybe funding will come and it will be revived. I don't care though, I won't stop whether I am paid or not. My passion is to see the difference in the children's lives.

Cathie Archbould

Immaculate Nakyanzi

Kkingo Sub-County, Uganda

When hiv and aids came to my community, it hit my life very hard. My two parents died from AIDS, and most of my brothers and sisters. In my own family, my husband died, and I also lost two children to AIDS – Jane Nakalema who died at 24 years, and Keteregga Francis, who died at 20 years. My three other children are living with HIV and AIDS. I was left by myself, caring for the children—and grandchildren—in my home.

When all this sickness and death started to happen in my family, organizations like Kitovu Mobile didn't exist. There was nowhere to go to get support. I was all on my own trying to help everyone. I strained myself to get the medication, to go to hospitals, and to get food supplements to feed the sick and the rest of the family. There was such poverty in my family then. I lost the support from my parents, husband, brothers and sisters. The expenses were so high and so much of my time was spent caring for the sick. We couldn't farm the way we did before. The gardens became bushes, and there was less and less food. The education of my children and grandchildren was affected.

It feels so good to be able to give my grandchildren the simple things that are so hard to come by for grandmothers—uniforms, shoes, and enough food at home so they can have lunch at school.

And for me too, my own welfare was not good. I was so stressed and lost hope. It harmed my dignity to have to ask for loans from other people. I was losing so much weight and couldn't take care of myself, so people started looking at me as if I had HIV and AIDS. The feelings and the stigma were so bad, and I lost my friends and started keeping alone to myself.

In 2011, when Kitovu Mobile started helping us grandmothers, that is when things in my life began to change. The children are now back in school because I could make enough money from the crops to pay for the school costs. It feels so good to be able to give my grandchildren the simple things that are so hard to come by for grandmothers—uniforms, shoes, and enough food so they can have lunch at school.

My grandchildren needed special grief counselling, and I had help communicating to the girls how to prepare for their menstrual period, and support to talk to my adolescent grandchildren about building relationships and the reality of growing up in a community struggling with HIV and AIDS.

Kitovu Mobile also helped me get a good house for the family. The old house we were living in was in very bad shape. The door had collapsed, it was leaking and too cold. When it rained we had to stand on the veranda to keep dry. And it was not safe, the old house. The new house is so smart, and the compound is nice, with a whole garden full of greens. Thanks goes to God, there is an iron roof, and doors and windows, and everything is painted.

So many grandmothers are having land problems, and relatives are even taking their animals and selling them. Even in my solidarity group, two grandmothers have had their land grabbed.

We had so much trouble when the house was being built, though, from the in-laws, the grandsons of my late husband. They came and said to me "You, grandma, you are not supposed to build here. You go and build somewhere else." At first they tried to sell the land. They were pressuring me to stop building the house, so I went to the local leaders who intervened to try to save the situation. They gave me a letter to give to the resident district commissioner. It said to stop anyone who wanted to chase me from my land.

After the house was built, the in-laws came back and started separating the land, putting plants down as markers to show that all I was left, apart from the house, was a little part of land. They told me to stop encroaching on their land and to pay them rent. They said "You're a grandmother, you are only left with your grave, and the house the organization built for you, you have nothing here." At one time they came after us with machetes, and wanted to cut down all the trees in our compound, the mangoes and the jackfruit trees. But one of my sons joined with our neighbours and fought them off.

About four times, my in-laws threatened that they were going to kill me. I reported them to the police. The police asked for 10,000 shillings for transport facilitation to arrest the boys, but I only managed to raise 6,000, which I gave them. They took the money but did not act because I failed to raise the full amount. So then I went to the prison officer and got a letter from him to give to the local leaders and the boys. It warned them to stop any kind of violence to me, otherwise they would be imprisoned. At present, my relatives are not doing anything, although they told me they are waiting for me to die and then they will come take the land.

I still worry about the land and wait for what will come next. But for now, things are better. The children are fed and they are going to school. The health of my family is much better. Kitovu Mobile is counselling the children living with HIV to live positively, and at times they can help with some cash to pay for transport to go collect medicines, and help with food supplements. One of my daughters is also getting free ARVs from Uganda Cares.

But Kitovu Mobile doesn't have resources to help all the grandmothers, and for them transport to hospital still costs too much, and it is hard to get treated quickly. They suffer from hopelessness and loneliness—they're isolated because of the stigma. They don't know about nutrition and sanitation, and how to generate some income for themselves. They have problems with bad houses, and their grandchildren are not getting good educations. So many grandmothers are having land problems, and relatives are even taking their animals and selling them. Even in my solidarity group, two grandmothers have had their land grabbed.

I love the work of helping fellow grannies. I feel it has become part of my life and I love it.

That is why I am doing my voluntary work. I started when I joined Kitovu Mobile. They trained me as a contact granny and gave me the knowledge and skills to help others. I offer the grandmothers counselling and teach them about nutrition, hygiene, to keep in solidarity and dignity as grannies, and be hopeful. And I accompany the sick to the health facility. I love the work of helping fellow grannies. I feel it has become part of my life and I love it.

Cathie Archbould

Mama F*

Zimbabwe

My story begins in 1992, when I went to the doctor and got tested and found out I was HIV-positive.

When I found out, my mind was so confused, I couldn't think. I couldn't believe what was happening. I thought it was the end of the road, and I started crying. I thought about my son, who was two and a half years old at that time. Each time I looked at my son I started to cry. It was just a big blow to my life. I thought I was going to die, because in those days ARVs were not available and so many people were dying.

The doctor saw that I was so stressed and he tried to give me tablets for stress. But as a person who was working in a pharmacy at that time I knew people got addicted to those tablets, and I didn't want to be controlled by them. I just said to myself, "I will stand up and be strong and accept whatever is there."

When I got home my husband was there and I told him straight away that the doctor said I was HIV-positive and wanted to test him too. He started shouting at me "No! If you've got that HIV it's yours, it's yours and your doctor's. You're the ones with HIV, not me." I felt so bad, but when I went to work the following day I told my colleagues, and they comforted me. What happened next was a real shock. I saw a messenger of the court coming to me with a letter. It was a divorce letter with my name written on it. The same day I got the letter, my husband took all of his clothes and started sleeping in his spare room.

Divorce laws in Zimbabwe have a waiting period to encourage reconciliation. So we waited for three years. It was a stressful life staying with my husband under the same roof because he is an alcoholic. He would come and break down the door and beat me and shout at me "Yah, you're going to lose the kids and I am the one who bought this house, and you will be destitute."

The day of the trial came and we went to court. He'd stolen the copy of my HIV test results, and produced them in court when the judge asked why he was divorcing me. He said he was divorcing me because I tested HIV-positive and he was not. The judge asked him where his results were, and he had nothing to show. And then the judge said "You are not divorcing this woman for no reason. If she's HIV positive that does not mean you divorce her and then you get to stay in the same house. You must move out and this woman will stay in this house with her children."

When the divorce came through he was ordered to leave the house. But after the divorce, he lost his job, and came back asking for forgiveness. I was not happy, but he insisted that he had nowhere to stay, so I let him stay with me, in a different bedroom, until he could find another job. That was my mistake. Getting him to leave now is a real problem. He is insisting on selling

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* *This grandmother's name has been withheld to protect her safety – speaking out about human rights in Zimbabwe at this time may pose a risk.*

the house, and the divorce order only gave me the right to stay in the house while the children were under age, and now they are older so the law may force us to sell the house. I don't know what will happen next.

When my husband first started being violent to me, my doctor advised me to go to the Zimbabwe Women's Lawyers' Association to get a protection order. I did, but these orders would expire after a year. Later on, they gave me a five-year protection order. Now I was able to go to the police when he bothered me, but it hasn't been easy getting them to do anything. The real reason was that my husband bought them beer, and they would go drinking together. I had to report to another police station to get help because the local police station would not take me seriously.

So once I reported them to the police administration, their bosses, and then they finally did something. They took him and locked him up for a night, and the following day he was ordered to pay a fine.

But the problem keeps going on and on. Now my husband is always drunk and saying vulgar words to me and the children. He calls me names. And the police will not act. This has been going on for too long, since 1996. It is painful, and I am tired of it. I don't see a way forward or a way to have hope. The police and the lawyers' association have seen me come to them too many times. Sometimes my life seems like it is going down the drain. I have had trouble making ends meet, and I did not have money to go to hospital to check my CD4 count or feed the children.

After being helped, I said to myself, "I'm OK, what about the others?"

Chiedza is an organization in my country which helps me so much. I come to them every morning, and I also bring the children with me, and I talk with them. In June 2013, I started taking ARVs, because my CD4 count dropped too low. It has been difficult getting to the hospital. Before I came to Chiedza, I would go to the local clinic, but to check my CD4 count I had to walk three hours to the hospital and three hours home. I leave around 5 am, but that is a risk because you know there are people waiting for older people who are vulnerable. But I had no choice, I had to walk because there are long queues and you have to line up very early.

Suddenly I was responsible for five children: my son, three grandchildren and my niece. I didn't know where I could even look for money.

I finally started going to Chiedza after things got really hard. In 2005, I lost my job because the pharmacy closed, and then in 2006 I lost my daughter to meningitis and my brother to suicide, and had to start caring for their children. Suddenly I was responsible for five children: my son, three grandchildren and my niece. I didn't know where I could even look for money. It was a hard time for me, angering and aching me—how was I going to get through this, and send the children to school and clothe and feed them? And for myself too, I needed better food to survive.

Chiedza has welcomed me and accepted me into the organization. They help me with food and clothes and blankets. One of the children went into their nursery school, and Chiedza paid for tuition and uniforms so another child could go to school. I would go there every day and eat, and they would teach me and the other grandmothers skills, and to make products we could sell. It's so hard for older women, you know, because we are supposed to be relaxing at this moment, but instead we are now busy looking for jobs, selling vegetables, scouting for food because our children died and left a trail of grandchildren behind to look after. The whole day, grandmothers work for those children because we cannot see those children suffering and out of school.

I was at the end of the road and Chiedza saved my life. I was thinking of suicide, but each time I would go to Chiedza they would tell us "Don't be discouraged, you will get through. Look after these children—you are ambassadors, you were chosen by God to look after those children." So I looked at the children and thought about the right decision. If I die, what are they going to do? All of these people are depending on me, and these children, they need me, killing myself would be the worst ending. So just cancel that thought. I am going to live.

After being helped, I said to myself, "I'm OK, what about the others?" I took courses and trainings, and now I am a community worker with Chiedza. I tell people not to give up; they can come out of the worst situation.

The way I see it, this is my community and I must take care of it—and people must move, they must change. I won't accept bad things happening before my eyes, and I won't be quiet. I don't want crooked things, and I will try to make them straight.

I do a lot of advocacy with other women in my community about violence. I am also working as a paralegal, especially for the women who are battered. I'm not afraid to talk or lecture to people. I tell people, "Don't be discouraged, be strong, if you see something wrong, or even if your husband gives you a slap, report it." I always tell people they must know their rights. They mustn't be quiet. They don't tell the police, they don't tell their relatives, they don't tell their neighbours what is happening under their roofs. People listen to me and trust me, and know I will step in if something is wrong. I also tell them to find out their HIV status to know the right food to take and live a better life.

One of the hardest things is when there is violence against a grandmother, because they won't report it. Most of the cases go under the bridge because nobody reports them. These grandmothers in our culture have a tendency to say "Oh, what can I do, it's my husband, or my brother, or my son, or my daughter, or my grandson." It's not just the job of the person who is being hurt to help themselves; it is also the work of the community. The way I see it, this is my community and I must take care of it—and people must move, they must change. If I see something that is wrong, I go and report it. If the police don't take action I change the police station. And if the next police station doesn't take action, I'll report it to the police headquarters—until the case is dealt with. I have this determination to fight because I love my community and the children so much. I won't accept bad things happening before my eyes, and I won't be quiet. I don't want crooked things, and I will try to make them straight.

Cathie Archbould

Zodwa Hilda Ndlovu

Durban, South Africa

I'm the founder of a group named Siyaphambili, which means "going forward." It's a group that provides support for people living with HIV. Working with my community on HIV and AIDS became so important to me because of what happened with my own children, because of the very sad deaths they endured because of this disease.

When my daughter became sick, in 1999, there was so much fear and silence about HIV. In those days I was a nurse, working in the hospital's infection control ward, and the culture was not just about keeping things confidential, it was complete secrecy. Young people when they found out they were positive would plead with us, saying "Don't tell my mother, don't tell my father, it will kill them to know that I am dying." We would keep this information inside ourselves, although it was very painful to do. Mothers would beg me to tell them what was wrong with their children, and I could not tell them anything. Then that same thing happened to me. When my daughter was sick in the hospital the other nurses knew she was positive, but they felt they could not tell me, and they kept me in darkness. I was staying with a friend, another nurse, who was also caring for my daughter, and she finally told me. She said "Zodwa, I am telling you this because I know you for long, but you know that I must not tell you. Because if you can go to the hospital and say that I told you your daughter is HIV-positive, I am going to be expelled at work and lose my nursing certificate." So I knew then, but my daughter kept the HIV a secret from me until the day she died.

So soon after, my son killed himself. Like my daughter, he never told me he was infected with the virus. One evening I came back from my volunteer work and I saw that the house was burning. My son was inside the car port and he had taken a can of petrol, threw it over himself, and burned himself to death. At first I did not understand, and it was only a month later, when I was cleaning the house and taking all the mattresses out, that I found a letter from him.

Here I was helping other people to cope with the reality that their children were HIV positive, but I could not help my own son.

He wrote, "Mama, I could not stand that I am HIV-positive, and we have buried my sister in 2000, and now I thought you were going to bury me." That is when I cried. I did not cry on the day he died, but that is when I finally cried. I said, "Why should this child do this?" Because now I have got the knowledge. Though I know there is no cure, no treatment, I have got the knowhow of how to live with HIV, I could have helped him. Here I was helping other people cope with the reality that their children were HIV-positive, but I could not help my own son. He thought he was saving me from the pain of a killer disease, but this was much worse.

Now I was left with no children. That day I realized, well, in life you don't have anything.

I am going to work with this animal of HIV, I want to fight it. And I also want to help people. I want everybody to know what HIV really is.

And it did become worse before I could turn myself around. I was diagnosed positive, and my husband passed away. Finally, after everything that had happened, after all of this, I pulled myself together and said, "No, I don't want other people's children to die like my own children." This is what I told myself. I am going to work with this animal of HIV, I want to fight it. And I also want to help people. I want everybody to know what HIV really is. I will work until I reach my goal. I want to be happy. I am 62 years old now, and have so many years living with the virus. And I am not shy to say it. But I have had to fight to help others.

Sometimes HIV-positive people do have to fight not to be second-class citizens. Earlier, people could be expelled from work if they were openly HIV-positive. In 2005, I was working in a nurses unit funded by the Canadian Nurses Association. I went for a new post, and the manager of the union said "Zodwa, we are not going to give you a job here because you are HIV-positive and the nurses are going to get infected by you." I told him that I was going to get that job whether he liked it or not. I was not going to be discriminated against. Two weeks later, I was in front of the board to introduce myself, and one of the managers lowered his voice and said, "But Zodwa, I heard you are HIV-positive." I said "Say it out loud, don't soften your voice. Yes, I am HIV-positive since 2000. This is my HIV. I love it. It's in me and there is no way I can pass it to you." They were shocked, and I got that job. I worked for the one year contract and then I left them.

I was pushing very hard to work on organizing in my community, holding workshops for the whole of Malazi, all the people living with HIV. People got to know me—the Department of Health, the social workers. They would say "This is the Mama who is HIV-positive wanting to do workshops." At that time I was angry, maybe more than I realized, but it kept me pushing. One thing that helped me to clear my mind was joining other organizations, like the Treatment Action Campaign and the Gender AIDS Forum, where I could talk. I did not keep all of this struggle to myself and in my heart. When I finally made these workshops a reality, I started with me. I started with myself. I think that helped me, because I did not hide my status.

When we started this organization, Siyaphambili, we were just five women living with HIV. One of the first things I did was to set up a soup kitchen for the children of the four women I was working with. I ended up feeding about 40 children in my neighbourhood. I was using my own pension money. The numbers kept going up, and finally I was able to feed them out of the local councillor's office, instead of my home. But the local council still isn't giving me any money to pay for the food, and we're now feeding about 68 orphans every day. I have applied to the Department of Social Development, and they've promised they will do something, but there is nothing yet. I ran out of my pension money, all of the money I had from being a nurse, so now I go out and ask anyone I can for money for the food.

I'm also trying hard to get some money to help pay the volunteers who have been doing this work for so long. Everyone in my organization, including me, does the work for free, from our hearts. But how do they keep themselves going? I've been trying to get money from the donors, but so far (outside of the SLF) they haven't been willing to give us anything so that the volunteers can have an income for themselves.

For the soup kitchen I now have 17 volunteers. There are volunteers in my organization who also go out to the community to talk to people who are sick, and also we help the grannies who are staying alone. Because it is dangerous for them to stay alone, we visit them.

Grandmothers in my community are severely under pressure. Most of these women—if not all of them—find themselves raising as many as three, six or even eight grandchildren. They have no support financially or emotionally.

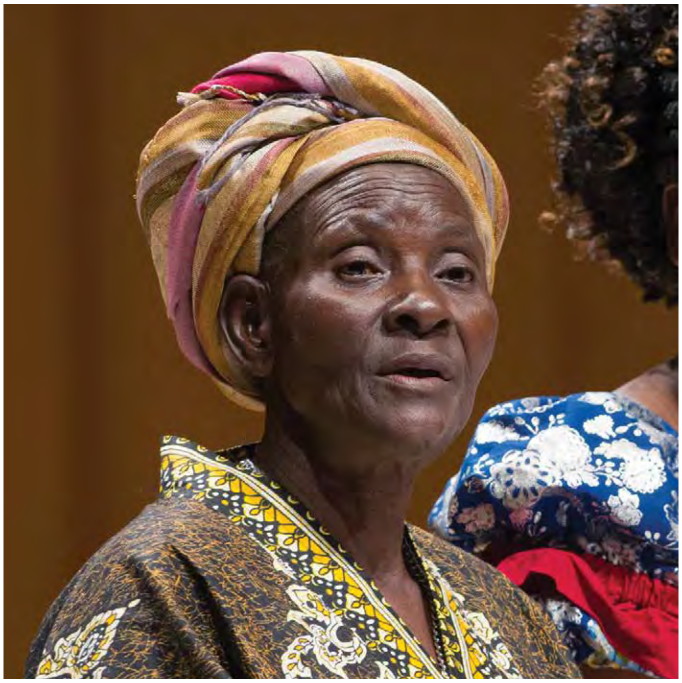
They are expected to feed, clothe, and school these children with the small government grant given to senior citizens in South Africa. To help them, we hold a support group for grandmothers on Tuesdays for skills development, mainly sewing. But the real benefit of the group is the sharing between grandmothers. We talk about our challenges and help each other grow, all the while enjoying a cup of tea. We also provide cooked meals to grandmother-headed households and struggling families—giving orphaned children food before and after school.

We are also doing counselling and education in our community about HIV and AIDS. Even though it is easier for some people to get treatment for HIV these days, many are afraid of taking the drugs. Now the problem is people say "We are going to take this treatment for life!?" They think it's a life sentence. But I convince them to take the tablets. Some people just want to stay in denial, and they don't understand that with the treatment they really will get a lot better. To them, taking the tablets means admitting they are sick. And many of them still don't want to disclose their status, and don't want to take the treatment because it will mean others will know they are positive. So the clinics have started sending people to my organization to get ongoing counselling while they are in treatment.

People need to understand that we are having difficulty in Africa because HIV is continuing. Even the children that are born today, we are giving them lessons about teenage pregnancy and such, but there are new infections. It's not going away. It is still a serious problem.

We really need to be doing a lot more of the door-to-door and giving people information. That's what my centre does, we go out to the community. If everyone could talk about HIV, there would be no fear. People would understand it. So it's important to recognize that this outreach has to continue. More people have to be helped, encouraged and supported if there is to be further progress fighting HIV.

Cathie Archbould



Magret Ongwen

Nyanza Region, Kenya

I SPEAK WITH PASSION because I know what wife inheritance did in my family.

It happens in the community because people still believe in it, especially people who have not experienced what I have experienced. It is something that is still happening apart from the very few people who really understand what HIV and AIDS is.

Wife inheritance is a cultural thing in the Luo community. If your husband died, you had to be inherited. You were supposed to be inherited by your in-law, a brother-in-law. This has gone on for a long time. The main reason I resisted being inherited was because I knew that HIV and AIDS had come to my home because of inheritance—my husband inherited a lady earlier who was infected, and this is how he caught the disease.

In the days when my husband got infected with HIV and AIDS, there was still no medication. I and my co-wives were just taking him to the hospital, we were not knowing what was going on with him. We spent all that we had on medication, even the land that we had we had to sell for treatment. It was almost at the last minute that we discovered that he was HIV-positive. But I tested negative, and I decided that I was not going to be inherited.

My husband still wanted us to be together as husband and wife and to make love. But I felt like I was going to get infected. My husband was angry and said from then on he was not even going to eat food from me, he wouldn't touch anything I prepared—it's like now I was not even part of the family. He did not beat me but he was so wild. He kept on chasing me and I would run all the time, and that's why eventually I decided to go and ask the administration office for help. The administration officer took his assistant and one community member and they went to the home to talk to my husband.

After my husband's death, it became like a real war in the family. It was not an easy thing. My family members threatened me because I refused to be inherited.

After my husband's death, it became like a real war in the family. It was not an easy thing. My family members threatened me, and they would not visit me in my home. They considered me unclean because I wasn't inherited. They did not confront me directly, but they kept on telling the children nasty things like that I was unclean. They were trying to pressure me through my children. They wanted to create a rift between me and my children. They were telling them that they would die because I wasn't inherited, and that they shouldn't eat with me because I was an outcast.

It was hard to go against my family and my community. But the main drive I had really came from what I experienced when my husband got sick. One minute he would be well and the next minute he would not even be able to move. So, when he died, I said to myself "What if I'm inherited and I go through the same thing? What about the children that I have, who will take care of them?" So that was my main drive.

My husband got sick in 1992, and he died in the year 2000. In the same year, one of my co-wives died. In 2001, another one died. In 2002, another one died. In 2003, the last one died. And when all of my co-wives died, they left me with their children. I now had six orphans, plus my own children and grandchildren to take care of.

The question was, how was I ever going to be able to support them? When I got married my husband was working with the Ministry of Water and he had money. Because of the sickness, he went and withdrew all of his savings, even his pension, and he used it all for treatment. He sold everything, even most of the land that we had.

I need to work very hard now to take care of my family. The food is not plenty but at least we can survive on what we have. I do farming and the children help me. I plant vegetables. I also plant mangoes and po-po that I can sell from the farm.

Most of the land we owned was sold, and even the land I was left with is not secure—the son of my brother-in-law is troubling me up to this moment that he wants the land. The land was demarcated with a fence and a title posted. He has gone and slapped off the title from the fence and claimed it is his land. I have reported the problem to the local administration, but so far no action has been taken. It's the usual bureaucratic process. They are slow to help me probably because they know I am a widow; other people they work for more quickly. They think other people's concerns are more important to deal with.

Paying for school fees and uniforms is also a big challenge. For one child I was lucky, I got a bursary for him from the local administration. But sometimes I can't pay so I have to keep the children out of school. Two of the children are out of school right now, and I'm trying to find the money for them to go back to school.

A lot of help with supporting the children has come from PENAF. I heard about them in 2007 and became a member. PENAF told us that being together and united is something good, and that we could save money together. They taught us about table banking, and if we save, save, save, within a year we can buy uniforms for the children. From my little savings from table banking, I am now able to buy clothes for the children, and sometimes PENAF also helps me with the uniforms, and with foodstuffs.

So my family is still here, and we are surviving. I love my children very much, and they are such a source of strength for me. The community had said that the children and grandchildren would die because I was not inherited, but all of them have survived. One of my sons has even been able to build himself a house. And I now have a great grandchild! This makes me happy.

I've proven, by my example, that the ideas people have about wife inheritance are not true. Your children will not die if you are not inherited. I've proven them wrong, because I even share the same house with my children. The people who used to say that I would be the death of my own children are now just looking at me. They also said that the children of women who aren't inherited will not get married, but one of my co-wives' daughters got married the other day, and everyone is marveling in the community.

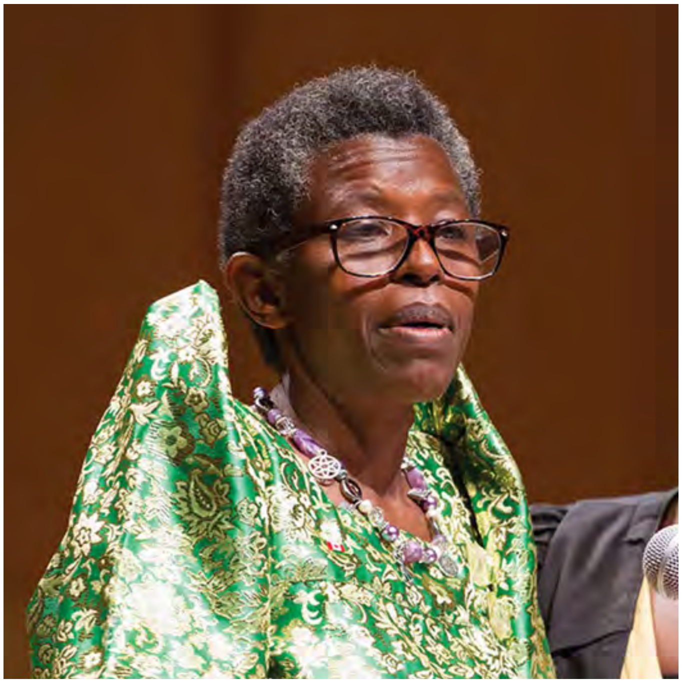
I have gained a lot of respect, and the young women in the community who have lost their husbands now consult me. There are women who have not been inherited because of advice I gave them. And there have been no deaths of the children in their homes, so they are doing well.

> ***I've proven, by my example, that the ideas people have about wife inheritance are not true. I have gained a lot of respect, and the young women in the community who have lost their husbands now consult me.***

Other people are also coming to tell us about the dangers of wife inheritance, such as the community health workers at PENAF who come to our group meetings. And I talk about wife inheritance at the PENAF meetings, and also when I go to church.

Things are changing, people are trying to understand, but wife inheritance is still existing. My community is now divided, some want to get rid of it, some still want to keep it. I believe that when people begin to see more examples, that's when the practice will start to really go away.

It was not an easy thing to lose so much of my family to AIDS. I would cry. Sometimes I would even be confused. I thank God that God did not leave me. The Catholic Church came to me and asked me to help in teaching, so that I would go and teach the children in school and forget about many things. When I'm with the children, and the church and the mothers, I feel good. Also, I've gone for the HIV test and I am very glad to know I am negative. But, most of all, what makes me happy is that even though the community said my children would die because I wasn't inherited, they're all still alive and still here with me.


Cathie Archbould

Mariam Mulindwa

Jinja District, Uganda

I am a leader in my community, and I am known as a strong and energetic woman. And I am! I admit that I do not like to talk about myself. When I meet with other grandmothers and they ask me about my hardships, my story, I tell them "Yours is mine… Yours is mine." I carry the same grief and burden as my peers, but I feel good when I do my voluntary work.

But I cannot deny that there is much sadness. I am sharing it with you today because I know it is important to speak about it. It is the story of my life that leads to my determination to be a leader in my community and bring strength and hope to other grandmothers.

Like so many others, my family has suffered so much because of HIV and AIDS. I lost my older sister, a teacher, who left behind six children—two of them twins who were not yet two years old. Before her death, my sister was ill for four years and bedridden for 18 months. Her in-laws chased her and the children out of her marital home. She returned home and my mother and I nursed her and gave her all the support that we could. But we did not understand HIV and AIDS, and there were no services or ARVs at that time. People were fearful even to talk about AIDS, and my family experienced stigma—especially from clan members. It was a painful time, and there was more to come. Last year, I lost another sister to AIDS. So now I have lost my two sisters, and they left behind a total of eight orphaned children. My older sister was the main breadwinner for our family. Our standard of living went down so much when we lost her.

I had to drop out of school because we were struggling to survive. We needed more security and support, and so I opted to get married at 19 years of age. I was fortunate because my husband was loving, but our home was like an orphanage—with so many orphaned children from my family and from his. They were so young, these children, and I had to work like a donkey to provide them with proper care—to feed them properly, and pay school fees for them. As they grow up, the challenges around school fees get deeper.

In spite of my efforts, I still could not afford the school fees. As a result, some of my girls became mothers at a very early age, which I regret. And so I became a young grandmother. This is not to say I hate being a grandmother, I just wanted better for both my children and my grandchildren.

And so I have 17 people in my house. My own children and all the orphans. Some of them have done so well. One niece whom I raised from a young age as my daughter, was so brilliant. She graduated from university with a B.A. in business and had a good job in Kampala; so much hope went with her. Last year, she too, got sick and passed away. I am before you today as a leader amongst the grandmothers, but I also carry the burden of grief that they do. I watch as my mother struggles with age and ill-treatment in a home where she is the first wife and cares for ten grandchildren, isolated and with high blood pressure. I care for my mother-in-law as she grows weaker with old age. I learned this way of caring for my family and community, from my father and mother, and now I carry on the role I saw them play.

When I meet other grandmothers and they ask me about my hardships, my story, I tell them: Yours is mine, yours is mine.

This community work led me to join PEFO in 2003, and I received support from them for the education of some of the children in my care—they gave as much as they could contribute to school fees, scholastic materials and lunch. There wasn't enough to support all of the children, but it lifted some of the burden off of me. I was then able to take on more volunteer work, and I took trainings on HIV and AIDS, livelihood programmes, and on creating a culture of saving funds among grandmothers.

Every Wednesday, I meet with grandmothers like me and we share our challenges and achievements in life. We discover that each and every one of us has a unique story to tell—about how life was before we received PEFO support, and what it is like now. I have learned so much about how to counsel and mobilize other grandmothers—encouraging them to have hope and to feel supported. There is so much intensity and sadness, and the grandmothers are exhausted hearing what and what about AIDS.

We use music, dance, and drama to entertain them, but also to raise awareness about HIV and AIDS, good hygiene and sanitation. Theatre and plays work because they help the grandmothers express themselves in a different way—they laugh, have some fun, and feel like part of the group. It is a skill to reach out to grandmothers who are grieving and isolated and help them feel better, understand their rights, their healthcare entitlements and access government programmes.

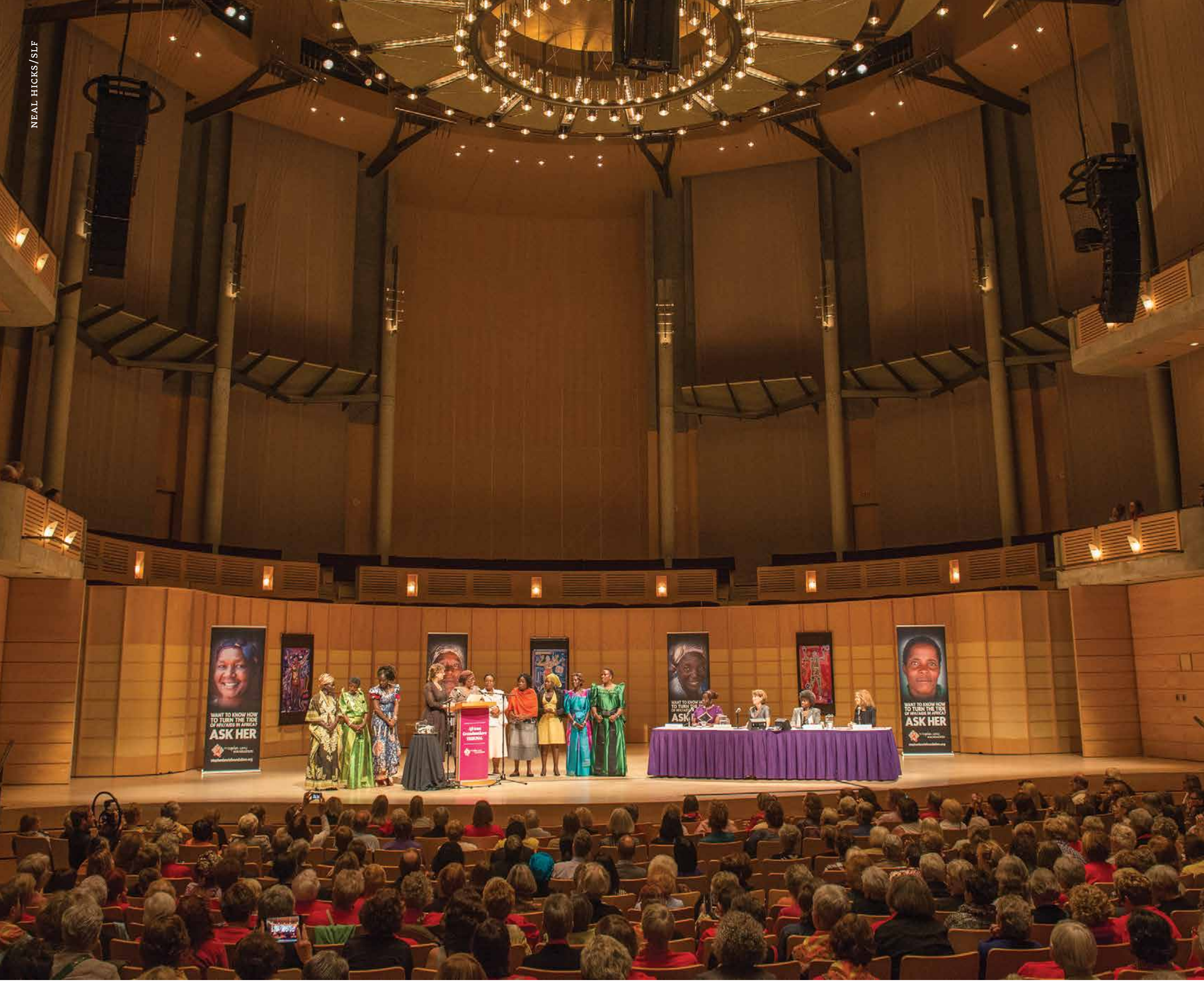
I know that it is important to advocate with my fellow grandmothers to participate and give their views in local councils... and I encourage them not to hold back! I have even learned how to convince them to make out wills and I feel very good about this. In the beginning, they were fearful that making a will would bring on their death. Now they have changed their minds, and it is important, because it means their children will be safe to inherit.

I feel the rewards of these efforts when I see the challenges grandmothers have overcome. In 2011, I won the Ms. Granny East Uganda award for this work, and it is a powerful advocacy tool for grandmothers. We invited many people to the celebration of this award, and we used the opportunity to show what an important role we play in the community and get more respect for grandmothers.

The local government invited me to sit as a member of the Sub-County Land Rights Committee. Since I have joined, all five of the cases we considered, mostly about land grabbing, were decided in favour of the grandmothers. It makes a huge difference to have a grandmother on the committee.

This respect is important in the community, but also to give us a voice in places where decisions about our lives are made. Recently, the local government invited me to sit as a member of the Sub-County Land Rights Committee. We set up teams to investigate the cases that come before us, and sometimes we can settle them ourselves. If not, the magistrate comes in every two months from the high court and works with us to come to a decision. Since I have joined, all five of the cases we considered, mostly about land grabbing, were decided in favour of the grandmothers. It makes a huge difference to have a grandmother on this committee. Before I was there, grandmothers would often give up, sure that no one would listen to them because they were too old and didn't have money for bribes. But now, grandmothers are more comfortable about raising their land issues with the Committee. They feel they'll be safe and understood.

I know the work is not finished yet, and that there is more to be done. I also know that other grandmothers take strength and hope from coming together, and from seeing me in a role of leadership in the community. So I feel proud and happy to know that my people are being served.



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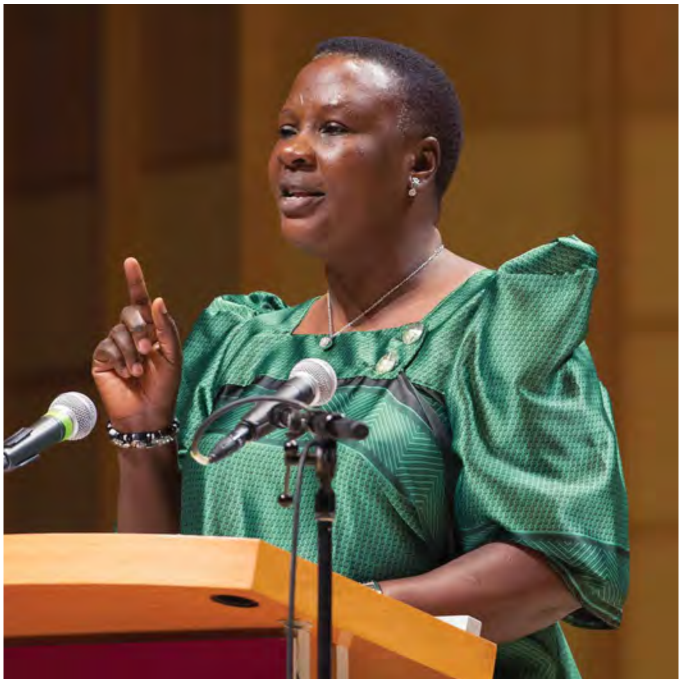


Cathie Archbould

Robina Ssentongo

Executive Director,
Kitovu Mobile AIDS Organization, Uganda

Kitovu Mobile was started in 1987 by the Medical Missionaries of Mary, to provide medical, psychosocial, and spiritual support to people infected and affected by HIV and AIDS, through a mobile service reaching far into the rural hard to reach areas. The conviction driving my organization's work is that people suffering from HIV and AIDS should be cared for close to where they live. For this reason, we are committed to strong community involvement, and Kitovu Mobile has more than 750 community volunteers who work with us to accomplish our mission in seven districts of Southern Uganda. We have helped to change the lives of thousands of people, by ensuring that a continuum of care reaches them directly in their communities—extending from general healthcare, to healthy living, to good ART management and to economic empowerment that helps people struggle out of the 'poverty bind'. Our vision is to see empowered communities that are able to cope with HIV and AIDS and its impacts.

We began our Grandmothers' Support project to respond to the desperate circumstances of so many of the grandmothers who have been left with responsibility for taking care of orphans and other household dependents as a result of AIDS.

Especially for the poorest grandmothers, the burden can be overwhelming. Healthcare services for older persons are inadequate, and even where they are available, grandmothers have to travel long distances to access them. They lack all of the basics, such as food, shelter, clothing and security.

Especially for the poorest grandmothers, the burden can be overwhelming. Healthcare services for older persons are inadequate, and even where they are available, grandmothers have to travel long distances to access them. They lack all of the basics, such as food, shelter, clothing and security. Grandmothers also lack the key resources, such as land, other assets and capital, needed to generate income to sustain themselves. They are often seen as not credit "worthy," and can be exploited in the marketplace due to their lack of information. Most of the grandmothers rely on subsistence farming, and many can't afford to meet their daily needs. And their own human capital is depleted by age, poor nutrition, sickness, overwork and social isolation.

Grandmothers are frequently abused in the community, but rarely seek legal support because of limited knowledge and inaccessible and unresponsive legal systems. In the community, AIDS has broken down the social network and the respect that should be given to the older generation. People ignore the grandmothers' needs, thinking that because they are old the effort would be wasted, and they are excluded from mainstream development programmes. The grandmothers caring for orphans have become one of the most vulnerable groups affected by the HIV and AIDS pandemic.

Kitovu Mobile is doing everything we can with the resources we have, but the great majority of poorest grandmothers are simply beyond our reach. I'd like to speak with you today about some of the most pressing healthcare-related needs so many grandmothers are still facing, and what must be done to meet these needs adequately.

Most grandmothers don't know very much about HIV—how you get infected, how you prevent infection, how to manage infection, or to go for testing themselves. They really don't understand the importance of having their own HIV tests done. Then, for those who are willing to get tested and treatment, there's a real problem accessing public healthcare. The facilities are often located too far away, and the grandmothers often have limited mobility and no resources to pay for transport. When they can get themselves to a facility and get a prescription, the medicines may be too expensive, or, if they are free, they are often out of stock at public facilities and need to be purchased from private clinics or pharmacies.

The grandmothers caring for orphans have become one of the most vulnerable groups affected by the HIV and AIDS pandemic.

Grandmothers who have many health problems can wait for hours and hours in line ups, and at times do not understand what they are being told. Many of the medical personnel are not warm in receiving the grandmothers. They feel "this one is already old" and not worth helping, and sometimes a bribe is even required to get adequate care. This makes it impossible for the grandmothers, who are very vulnerable. The attitudes are often a big problem, especially in public facilities where the staff are not trained in geriatric care.

We really have to change the way that healthcare is being provided to the elderly in Uganda. The government already has taken the first steps. In 2009, the government launched the National Policy for Older Persons, and followed this in 2011 with the National Plan of Action for Older Persons 2011-2015. A law establishing the National Council for Older Persons came into force in 2012. But the plan is still not known by many people, and it still hasn't been put into action. One of the most important parts of the plan is that older persons are supposed to be elected from the village level to speak for the older persons at the national council about their rights and needs and what should be done.

This has to happen as soon as possible, so that we can start designing and implementing the strategies that will give grandmothers access to the services they need. Once the national council is actually up and running, and it's given the mandate and resources it needs, it could really become the voice of older persons in Uganda. There is already the National Network for Older Persons of Uganda (NNOPU), a civil society umbrella body that represents older persons, and provides a strong and united advocacy voice. However, it is not funded by the government and lacks the resources to undertake and fulfill its mandate adequately.

But let's be very clear here. Yes, it is important for us to press for action with the government so that the national plan for older persons is actually implemented. However, a national plan certainly doesn't replace the need for community-based care. Instead, this plan should be supporting and up-scaling the type of community-based care that organizations such as Kitovu Mobile are providing right now.

Through years of experience, we've developed a process for working with grandmothers that really does help them turn their lives around, even in the face of so much difficulty.

We start by tackling the isolation suffered by so many grandmothers. Some feel stigma from the community because of HIV, but they also stigmatize themselves. They feel they are bad luck because they have lost so many children. They're worried that they might have HIV, and they don't reach out to others. And the people around them have no interest and ignore them. They don't understand what grandmothers need, that they need encouragement and help through their bereavement, that they're caring for so many orphans, and that their houses are collapsing. So we work with the communities to educate them about the problems that the grandmothers are struggling with. And then we make the community part of the solution.

We've developed a way of working with grandmothers that really does help them turn their lives around, even in the face of so much difficulty.

In every new community, we ask them to identify the 100 grandmothers who have the greatest need and should be helped by Kitovu Mobile's programme.

The first step for the grannies that the communities pick out is to get to know their general status—their medical problems, healthcare needs, whether they have enough food to eat and if their house is safe. We help right away with urgent needs like medical care, food and housing. Then we think about their emotional needs. We set up solidarity groups for the grandmothers so they can share, know they are not alone, and see that there are others with the same, and even worse, problems. They need bereavement counselling to mourn the deaths they have suffered. They share and cry until they are able to cope. When the person has been helped medically, socially and emotionally, she is no longer hopeless. She can say to herself "I have these orphans, but it's not the end of the world, there are people who care, and the children are growing." That's when we start to give them training. We say to them "We gave you maize and flour in year one, but you have to find a way to live—what skill do you think you can learn?" They choose to raise pigs or goats, or to make products they can sell in the market. We empower them to realize they can make a livelihood for themselves, and give them assistance to do it. And we train some of them as "contact grannies", who can transfer their skills to their peers when we are not there. We lobby to get some funds for the grandmothers' solidarity groups, and they save their own funds as well, so they can help one another. This way they are not dependent on the project for assistance, because they build their own community support.

The grandmothers' groups get bigger and stronger as more members join—they may start with 25 or 30 people, but will grow to 150 people, all working to support each other. We also help the children to form clubs to get peer support, give them counselling, and behaviour change programmes, because the children of grandmothers can be in such chaos. Their grandmothers are tired and overburdened. We make sure that the children understand that they have to grow up in a good way, and work with their grandmothers to make sure their families are okay.

All these phases work together holistically to change the grandmothers' realities. Kitovu Mobile's approach gives them so much more than services—the grandmothers are regenerating and reclaiming their sense of purpose in life.

CATHIE ARCHBOULD

Siphiwe Hlophe

Executive Director,
Swaziland Positive Living (SWAPOL)

THE STORY OF SWAPOL is closely linked with my personal experience. I learned about my HIV status accidentally in 1999 after taking a medical examination as a pre-requisite for the award of a scholarship to study abroad. When I went for the medical examination, I did not know that I was also being subjected to an HIV test and that the scholarship could not be awarded to anyone with HIV. The consequence of my HIV status meant that I could not be awarded the scholarship. Subsequently, I became a victim of stigma and discrimination among family and community members. I experienced pressure that resulted in leaving my in-laws' home. As a coping strategy, I joined with four other women in 2001 and started an organization for women living with HIV and AIDS who were encountering stigma and discrimination from their families and community members. It was named Swaziland Positive Living which became popular by its acronym—SWAPOL.

While three of us who co-founded SWAPOL are still alive and involved with activities of the organization, two are deceased. We've grown a lot since those early days. Now SWAPOL serves 55 support groups in 55 rural communities with a membership of over 11,000 people. We support women living with HIV, orphans and vulnerable children, and the grandmothers. The mission of SWAPOL is to improve the quality of life for people, particularly women and children, infected and affected by HIV and AIDS in Swaziland.

We respond to the healthcare needs of people living with HIV and AIDS using an integrated approach, that also looks at their food security, the policy changes needed in areas such as healthcare delivery and health financing, the psychosocial challenges faced by orphans and vulnerable children, and the problems that exist across all sectors because of gender inequality.

We understand that the only way to resurrect life and improve the quality of life for grandmothers and the children in their care is to understand them as whole human beings.

Grandmothers face complicated health challenges in the context of the pandemic. Aging with HIV and AIDS is more difficult than aging with chronic age-related conditions such as heart disease and diabetes. We have found that the only way to ensure their health is properly cared for is to engage very directly with the grandmothers in their communities. SWAPOL has established 30 accessible treatment sites, and trained 110 community caregivers who conduct home visits to the grandmothers. We assist them with all of their healthcare needs, from taking medication, to screening for age-related diseases such as heart disease and diabetes.

I want to give you one very simple example of the difference that community-based care makes. Recently, we worked with a 62 year old grandmother who went to a healthcare centre for treatment; however she was afraid to disclose her HIV status. The nurse asked the grandmother "What is really troubling you?," but the grandmother would not say anything to her about the sickness. Fortunately, this grandmother was accompanied by a SWAPOL caregiver, who took her aside and had a discussion with her about the importance of disclosing her HIV status. She comforted and encouraged her, and the grandmother was able to disclose her status and get the proper treatment she needed.

Because SWAPOL works in the heart of communities in Swaziland, we can see the whole picture. We understand that the only way to resurrect life and improve the quality of life for grandmothers and the children in their care is to understand them as whole human beings. For example, if you include a grandmother in an animal husbandry project, but she can't have her own bank account without a man's signature, or if you're trying to improve the attendance of girls in school but grandmothers aren't getting the support they need to talk to girl children about sex and sexuality, you run into problems. You cannot properly implement any programme if you don't understand the individual challenges, and if you're not building community support and awareness. Once you do have this understanding, some of the solutions can be easy. With the 62 year old grandmother I mentioned, a few well-timed moments of advice and encouragement was all that was needed to get her into life-saving treatment.

Community-based organizations (CBOs) are deeply connected to their communities, and this is a very important factor in our success in fighting HIV and AIDS. My story and the story of SWAPOL are not at all unusual. Many of the CBOs were started by women who are HIV-positive themselves and have a close emotional and personal connection with the issue and decided to take action. In fact, CBOs have provided much of the fabric that keeps communities together. The sort of programmes the CBOs run—for example, helping the grandmothers come together in mutual support groups to strengthen themselves and each other—are part of rebuilding our communities. HIV and AIDS totally destabilized the traditional relationships and interconnectedness of rural life. At the same time as CBOs have been delivering essential services, we have been reconnecting people and redeveloping relationships, overcoming the fear and discrimination that were separating people and keeping them isolated. We're helping people recreate and rediscover the community bonds that have been there for generations.

We're striving to meet the grandmothers' basic needs, but now we are also working with the grandmothers to advocate strongly for their rights.

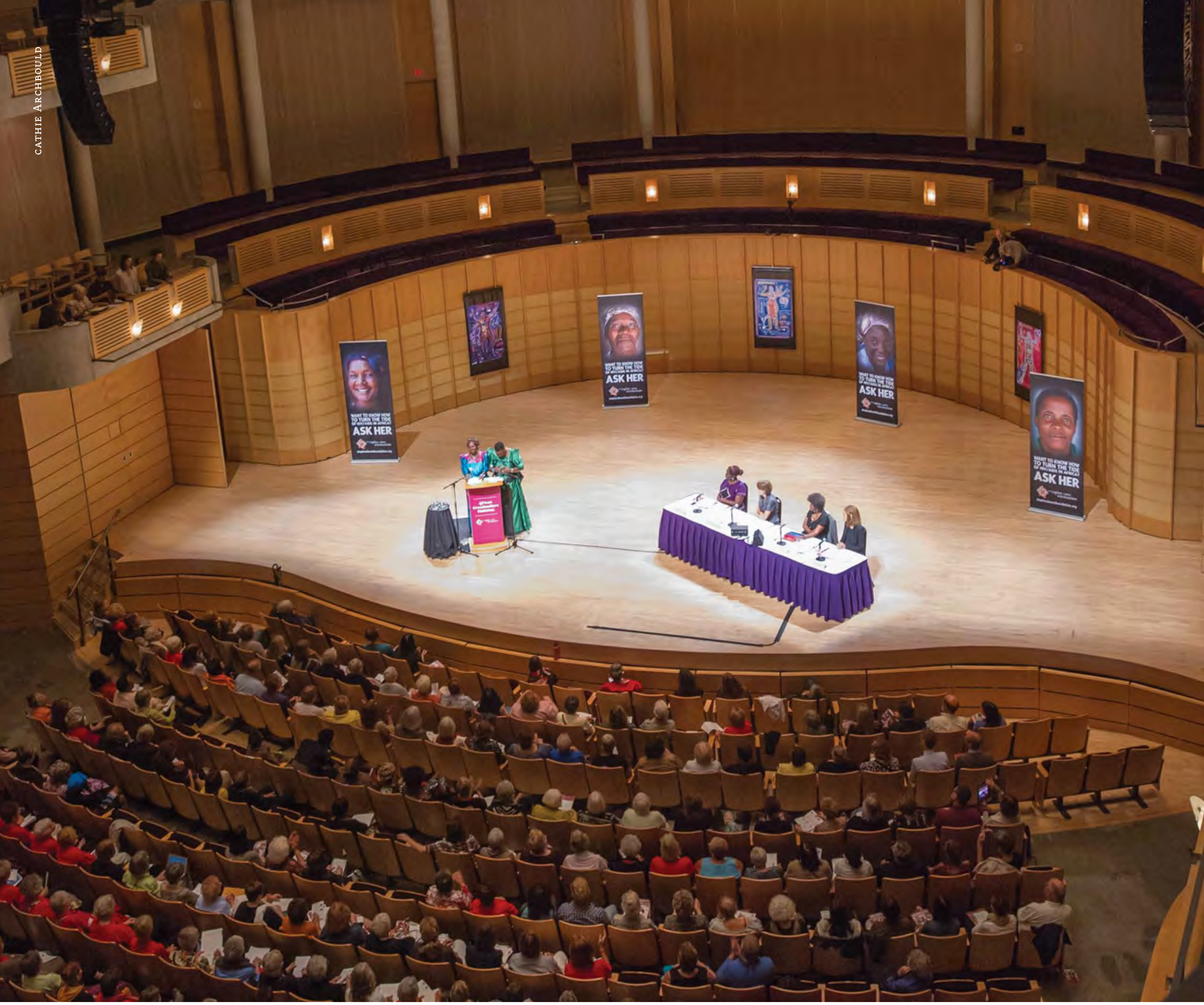
International organizations and donors need to better understand and respect the expertise of grassroots organizations. We have people living with HIV and AIDS on our staff and Board, so there is a real sense of community ownership. Our accountability is first to the community, and the community also feels itself to be responsible for making our initiatives successful. It's because we're actually consulting with and creating the solutions with the community members that we're able to come up with effective answers for the challenging problems created by the pandemic. It's about accountability and commitment on both sides—the CBOs and the communities themselves. That dynamic is essential for making things work.

Grassroots organizations grow and change in response to the new challenges and opportunities people are facing. We still strive to meet grandmothers' basic needs, but now we also work with the grandmothers to advocate strongly for their rights. In 2006, when the Stephen Lewis Foundation hosted the first Grandmothers' Gathering in Toronto, the grandmothers were grieving, they were overwhelmed by the responsibility for their orphaned grandchildren, and desperate for counselling and emotional support. They were dealing with the impact of being thrown into deep poverty because of the death of their breadwinners. But now, over the past six years through projects and organizations like SWAPOL, the grandmothers are no longer completely exhausted by the struggle to survive. They are getting just enough support to send their children to school and put food on the table. As a result, in community after community where this support has been flowing, grandmothers and the community-based organizations supporting them have been able to invest energy into bigger, more systemic changes.

Community-based organizations will always be necessary. We are—across the continent—the lifeline and advocates for grandmothers and the children in their care.

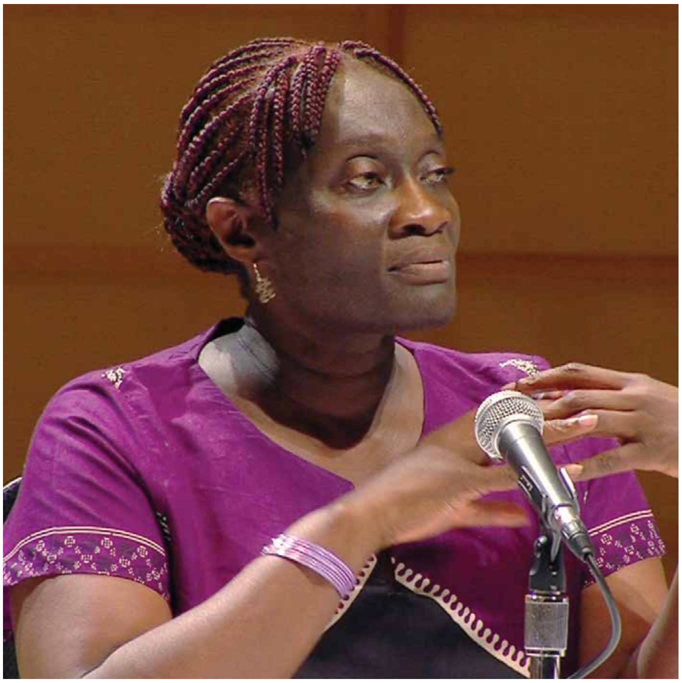
Community-based organizations are now mobilizing around a number of key legal and policy changes that need to be made to improve grandmothers' lives, in areas such as violence against women and housing security. For SWAPOL, advocating for pensions is at the top of our priority list. Grandmothers were hit so very hard by the poverty that followed the deaths of their husbands, sons and daughters, and the demands of caring for the needs of their grandchildren. SWAPOL has been doing what it can to help the grandmothers with grants and income-generating projects, but the reality is that we cannot adequately meet all of the grandmothers' needs in this way. The long-term solution must be to change the way that pensions are being granted to the elderly in Swaziland.

The reality is that even with the gains that have been made, and those that might come—from treatment as prevention, to the availability of drugs for all who need them—community-based organizations will always be necessary. We are crucial for ensuring access, and for understanding and addressing the challenges faced by grandmothers and others in the community, so that they can benefit from these developments. Whether it is bringing about behaviour change, healing lives that have been damaged by so much loss, breaking through stigma, or simply understanding what works and why, we are—across the continent—the lifeline and advocates for grandmothers and the children in their care. We carry this responsibility with great concern and love, but we have done it without adequate support or recognition of our expertise for far too long. The grandmothers are at the heart of the pain and suffering, but we are also at the heart of the response to AIDS in our countries. It's time that we, and the organizations run by and for us, had all the support we need.



Cathie Archbould

Judges' Statements



NEAL HICKS/SLF

Theo Sowa

Chief Executive Officer,
African Women's Development Fund

GOOD AFTERNOON. I'm Theo Sowa, one of the Stephen Lewis Foundation's African Advisory Committee members and the head of the African Women's Development Fund. It has been sobering, illuminating and inspiring to listen to these amazing women speak.

> ***Without the African grandmothers, the world would not have been made so gloriously and yet so painfully aware of the power of love, of care, of anger, and of commitment. We thank you.***

What would the world look like today, if grandmothers hadn't taken the initiative when no one else would? Hadn't stepped in to care for their families and neighbours as they were decimated by HIV and AIDS? So many communities would not have been able to survive. A generation of children would have been left so deeply traumatized and neglected that they would now pose a danger to themselves and to others. That possible future didn't become a reality. We have the grandmothers to thank, and it is high time we did thank them. Not only those grandmothers whose testimonies we heard today, but the thousands of others they represent—in Africa, but also in other parts of the world. Without you, African children, African communities, and African nations might well have succumbed to the catastrophic impacts of HIV and AIDS. Without you, the world would have taken even longer to learn the crucial lessons that have led to us beginning to win the struggle against the pandemic across the globe. Without you, the world would not have been made so gloriously and yet so painfully aware of the power of love, of care, of anger, and of commitment. We thank you.

Through the grandmothers' testimony today we have learned just how much they have been able to accomplish for their families and communities, drawing only on their own hearts and spirits, and the support of those grassroots NGOs who understand the important role grandmothers can play. Grandmothers are feeding whole neighbourhoods of children, and monitoring their health and well-being. Grandmothers are advocating for an end to discrimination and violence, encouraging women to claim their rights, and helping them get protection and redress. Grandmothers are helping to remove the stigma and ignorance that hold people back from treatment and testing, and giving the day-to-day support that keeps people in treatment. Grandmothers are advising on the boards of NGOs, and they are becoming part of local governance. Perhaps most significantly, grandmothers are joining together, forming mutual support groups and creating their own organizations, to help advance the work they are so committed to. In short, grandmothers are showing the most inspirational type of leadership—and they deserve support to make that leadership count fully.

Let's talk again about possible futures. What would the world look like if more grandmothers were given opportunities and support to help them to take on leadership roles? With 100,000 more women like Mariam sitting on local land councils, would property grabbing come to an end? With the counselling, support and encouragement of 100,000 more women like Zodwa, how much more quickly might we overcome stigma and fear, and get more people into treatment? Would the advocacy of 100,000 more women like Magret bring wife inheritance to an end? We'd surely be a lot closer to reaching those goals.

Here are four steps that can and should be taken right away:

- Grandmothers should be included on all of the bodies that make HIV and AIDS-related decisions—national HIV and AIDS planning boards, but also hospital and clinic administrations, and NGO advisory bodies.
- There should be greater representation of grandmothers in local- and community-level decision-making processes, especially on bodies that make decisions about crucial issues affecting their lives, such as land committees.
- The grassroots NGOs that are facilitating grandmothers' leadership should be given targeted funding to expand their work.
- The grandmothers' own organizations and mutual support groups should be given greater recognition and direct funding of their own.

Yet we have heard that this leadership comes in the face of severe challenges—horrific violence against grandmothers, women and girls; insecure housing and violation of land rights; and minimal and insecure funding for initiatives that have saved so many lives.

The pandemic has brought a crisis of mass eviction into grandmothers' lives.

We've heard from the grandmothers about the enormous importance of decent housing and rights to land, and about the extreme poverty and physical endangerment that they can face when these essential supports for a decent life are taken away. Having well-built, secure shelter, with land nearby that can be farmed for crops to eat and to sell for additional income, is what has made it possible for so many grandmothers to support themselves and their grandchildren, and to access the level of nutrition they need to live more healthily with HIV. Without these essentials, well-being, indeed survival, is jeopardized.

The pandemic has brought a crisis of mass eviction into grandmothers' lives. The stories that Immaculate and Magret have shared with us, about their struggles against land and property grabbing, are not unique. They have been repeated in community after community, across the countries of sub-Saharan Africa and reflect a pernicious intersection of HIV and discrimination against women. The addition of age and impoverishment makes for a dangerous vulnerability, as HIV entered into social arrangements that already discriminated against women and placed them at a disadvantage in terms of their security and entitlements. The system of customary land ownership that dominates in many areas is structured according to tribe, clan and family lineage, in ways that marginalize women and in many cases exclude women from the direct acquisition of land, on the assumption that their needs will be met through their position within their families. When this connection is severed—for example, because of a husband's death due to AIDS, or because a woman is divorced or abandoned following the disclosure of her positive status—grandmothers are left in dangerously vulnerable positions.

The law relating to land and property ownership in sub-Saharan African countries is complex and evolving. Most countries inherited a mix of customary and colonial law at the time of their independence, and have since enacted a succession of legal reforms. So it is by no means true that all of the women who are being dispossessed of their homes and land have no legal claims to make. Indeed, Kenya's constitution has enshrined women's rights at the highest level of authority in the country's legal system, requiring that gender discrimination be eliminated in all laws, customs and practices related to property and land, and requiring that new laws be enacted to recognize and protect matrimonial property, especially the matrimonial home, upon the termination of marriage. And Malawi's new Deceased Estates Act protects widows' and children's share in the estate, making property grabbing a punishable offense.

The challenge that grandmothers are confronting is not simply that they have no legal rights—often it is that these rights are not being recognized and enforced in their communities. In one study conducted by the Centre on Housing Rights and Evictions, which surveyed 240 women infected or affected by HIV in Ghana, Kenya and Uganda, only two had managed to successfully regain their property by legal means. Many grandmothers are not able to afford the high cost of bringing a legal claim. They also face justice systems that favour people with money, while enduring harassment from their in-laws and struggling with the day-to-day burden of the disease and care for their grandchildren. Many are overwhelmed by this many-sided assault, and just give up. But not all. As we have heard today from the grandmothers' testimony, support from grassroots NGOs, women's lawyers' associations, legal aid, responsive police officers and local officials, and gender-sensitive land tribunals—especially those that include grandmothers as decision makers—can make a tremendous difference.

The grandmothers have a right to expect much more. They should not be left on their own to navigate complex, discriminatory and dysfunctional legal systems, all the while trying to hold the onslaught of their relatives' aggression at bay, and searching desperately for their grandchildren's next meal.

Women's human rights to land and housing are well recognized in international law, if less so in practice. UN intergovernmental resolutions on human rights and HIV and AIDS have repeatedly called for greater protection for women's property, land and housing rights, and have highlighted the special vulnerability of women to violation of these rights in the context of the HIV pandemic.

The consensus is even stronger and clearer at the regional level, as reflected in the African Charter's protocol on women's human rights, which not only reinforces the international guarantees relating to housing and property, but sets out a specific right to inheritance for women. Article 21 of the Protocol states that women shall share equally in their husband's property, that widows have a right to continue to live in the matrimonial home, and that women have an equal right with men to inherit property.

The poverty and desperate need the grandmothers have been describing to you today is not some tragic misfortune that has befallen them. We need to be very aware that this situation is not accidental. Grandmothers are losing their homes and their land because they are women. It has been commonplace for policy makers to speak of gender-based discrimination driving the pandemic, and of HIV and AIDS having a woman's face. But the lived reality that stands behind those phrases is of older women and their families made destitute, with no recourse. The intersection of HIV and discrimination against women has not just made it easier for the disease to permeate communities, it is fanning the fires of discrimination in a most alarming way.

Here are some steps that can and should be taken right away:

- National constitutions should guarantee women's rights to housing and land, and their equal rights in the context of inheritance and the dissolution of marriage. Constitutions should also recognize that these rights apply both to state-run legal systems and to customary and traditional systems.
- National laws and policies should be adopted that protect women's land and property rights, and leaders of customary or religious legal systems must undertake reforms to ensure their property and inheritance practices do not discriminate against older women.
- The protection of women's land and housing rights must be integrated into national HIV and AIDS plans, including measures to ensure that marital property is divided without discrimination upon separation, divorce or death, and to ensure the restoration of all land and property that has been illegally taken.
- Courts, policing and legal aid must be made more accessible and responsive to older women's claims of violations of their rights.

Finally, no serious discussion about protecting the human rights of African grandmothers can be had without addressing the question of funding. The grandmothers who shared their testimony today, our expert witnesses, and my fellow Tribunal judges have all laid out a compelling case for urgent action. The exploitation, marginalization and abuse of these women, who are giving so much to their communities, has to be recognized and remedied. But change takes money.

UNAIDS issued some revealing statistics last year, about the money that is being spent on HIV and AIDS related initiatives that target women.[1] The first shock: only 85 of the 127 countries who prepared progress reports indicated that any money was being spent on programmes that specifically target women. The second, even greater, shock is the utterly trivial scale of the funding. The total global figure for women-specific spending in 2012 was US $288 million. UNAIDS broke this figure down into four further categories – 1) ending new infections in children and keeping their mothers alive; 2) programmes for sex workers and their clients; 3) programmes to reduce gender-based violence, and; 4) "other" programmes for women. US $203 million of the total $288 million is being spent on the first category—but as UNAIDS observes, these programmes don't necessarily include continuing HIV treatment for women, or address their primary prevention needs. To be quite honest, the vast majority of the funding under this category goes to the benefit of children, and not to their mothers. Only US $20 million was reported worldwide last year for HIV-related anti-violence interventions and other programming directly targeting women's concerns.

[1] *Women out loud: How women living with HIV will help the world end AIDS*. Geneva, UNAIDS, 2012.

What is also very telling about the UNAIDS report are the statistics that don't appear. For example, the statistics on funds allocated to treatment and prevention programmes are not disaggregated by gender. And none of the statistics that are being collected—even the information on programming that targets women—tracks the percentage of HIV and AIDS money that reaches grandmothers. The total resources being allocated to women are shockingly low, and within that small pool, the bulk of the funding is going to issues involving younger women, such as vertical (mother-to-child) transmission.

The current HIV and AIDS funding picture is also quite troubling because of the very limited support that has been allocated to the care and support work of local, grassroots NGOs.

The exploitation, marginalization and abuse of these women, who are giving so much to their communities, has to be recognized and remedied. But change takes money.

When we hear about funding for AIDS in Africa, the focus has always been on the provision of drugs. Of course this is desperately important, since just over 50% of those who need the antiretroviral drugs for AIDS are receiving them, and only 25-29% of the children who need pediatric ARVs have access to them. But drugs don't deliver themselves, and drugs alone won't heal the damage done by the pandemic. Much more support is needed for the community-based organizations that have become the backbone of the healthcare response to AIDS on the ground.

Donors must overcome their reluctance to fund smaller, grassroots, community-based organizations (CBOs). As we have heard from the testimonies of the grandmothers and the experts today, community-based organizations have become the lifeblood of communities affected and infected by the HIV and AIDS pandemic. When the traditional networks of relationships, that had sustained people for so many generations, were breaking down, it was the CBOs that found new ways of supporting and caring for members of the community. And they set in place new relationships and frameworks—such as the grandmothers' mutual support groups—that brought people together again to work for the common good.

This is only natural. The CBOs are integral parts of their communities. It is the community-based groups—not the big international organizations—that are talking with the grandmothers every day, visiting and treating the grandmothers every day, counselling and encouraging them, and working hand in hand with them to find solutions to their problems. It's also the CBOs who are helping grandmothers to find their own voices, to organize themselves, and to become powerful advocates for changes, such as pension reform, that will make a lasting difference for their lives.

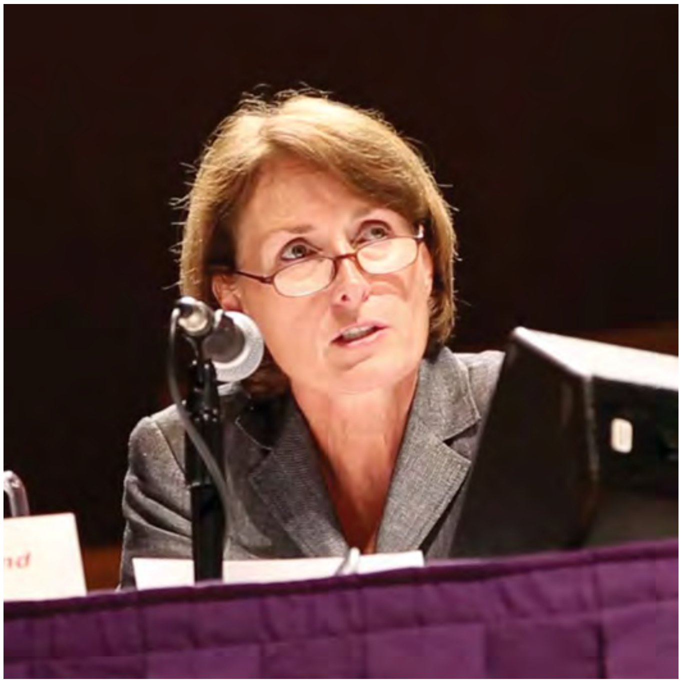
When the pandemic first struck, state-supported healthcare systems were completely overwhelmed. Community-based and home-based care initiatives emerged to meet the urgent needs, and at present they are the source of the majority of HIV-related care services. But meaningful financial support did not follow. And in particular, financial support most certainly did not flow to the grandmothers who are on the frontlines of delivering so much of the care needed by their communities.

Feminists have long campaigned to get recognition and compensation for the unpaid care work that women do all over the world. The situation of the African grandmothers in the context of the HIV and AIDS pandemic is possibly the most extreme example we have today of this discriminatory economic exploitation. While the major donors do now seem poised to improve their support for community-based healthcare—because of the discovery that treatment is prevention—we need to be alert to the very real danger that women's "invisible" care work will continue to remain invisible in their new funding plans. Mary Ellen has noted some of the specific measures needed to end the economic exploitation of grandmothers in their role as primary caregivers, and these should be made concrete requirements for any donor-funded community care programme.

At present, donors aren't funding initiatives designed to reach older women, and they aren't even tracking what portion of their resources ends up being spent to the benefit of older women. The inclusion of grandmothers as a designated target group in the donors' policy documents and multi-year plans would certainly be very welcome, but given their track record this alone would be unlikely to translate into very much money on the ground.

The ultimate goal would be state-funded pensions for the grandmothers. But the fact that not all sub-Saharan African countries may be able to establish these systems right now can't be treated simply as "their" failure—and it can't then be taken as an excuse on the part of everyone else for abdicating on the response to the gross violations of grandmothers' rights, and the extreme poverty to which they are being subjected. In the face of such pressing need, the donors must step in to help develop shorter term income security solutions.

NEAL HICKS/SLF



Mary Ellen Turpel-Lafond

British Columbia's Representative
for Children and Youth

One constant in the life stories that all of the grandmothers have shared with us today is the extreme depletion of their resources, in every sense—economic, emotional, physical and spiritual—because of the challenges they have faced struggling to support families devastated by HIV and AIDS. The great strength, wholehearted commitment and continuing resolve they have demonstrated in such desperate circumstances, tells the world something very important about the human spirit. No one can remain untouched after hearing these stories.

But we, collectively, have an obligation to respond with more than simple admiration for the heroism of these individual women. The burden that grandmothers across sub-Saharan Africa have been carrying is a highly unjust burden, and it should be placed back onto the shoulders of its rightful owners.

The starting point must be clarity about how it is that African grandmothers came to be solely responsible for the well-being of so many people. Two crucial things happened when HIV and AIDS so violently entered African communities. The first was the loss of a whole generation to AIDS, the children's mothers and fathers, their aunts and their uncles. African culture has long been grounded in a social order of close knit, mutually supportive, extended families, with the community being the main source of stability and security. But once adults in their 20s, 30s and 40s had died in such large numbers, these traditional networks ceased to function, and desperate needs arose. The second thing that happened was that, even with the social structure in disarray, the culture's spirit of mutual responsibility and support lived on. The children were not abandoned. Community members—the great majority of them grandmothers—stepped in. And they stepped in to care for these children regardless of what the limits of their own personal strength and resources might be.

> ***The grandmothers stepped in to care for these orphaned children regardless of what the limits of their own personal strength and resources might be.***

The grandmothers have told us today about the lengths they have gone to in order to support their grandchildren. Emptying their small savings, begging, farming small plots of land while holding off property grabbers, studying new skills to earn bits of income, exhausting themselves with piece work and day labour, loaning any money they have to each other through table banking. Local grassroots NGOs have done whatever they can, whenever they can, with their limited funds, providing bedding and food stuffs, seeds and fertilizer, repairing homes, paying for school fees, uniforms and books. It's rarely enough. These families are living precarious lives, under the constant threat of extreme poverty. One bad financial turn can lead to hunger, the end of the children's schooling, inability to access HIV treatment, or homelessness.

The grandmothers have also told us about their extensive work to help other people in need in their communities. They are running soup kitchens for the children and monitoring their health and emotional well-being. They're providing psychological counselling to people infected by HIV on how to live positively with the disease. They're giving advice to women and raising awareness about domestic violence, and harmful practices such as wife inheritance. They're running support groups for grandmothers. They're making sure that people infected with HIV know how to manage their treatment and nutrition, and can access medical care. But this too comes at a high personal cost. The grassroots NGOs they work with can't pay them salaries, and can rarely give them any money at all. Some grandmothers even end up having to draw on their own small pool of resources to help provide services to the community.

Let's talk now about human rights. The human rights to food, to income security, to housing, and to education are all enshrined in the international human rights treaties that nations around the world have ratified and endorsed. And these rights have been embraced especially by African countries, through the adoption of the African Charter on Human and Peoples' Rights, and in the detailed provisions on socio-economic rights contained in the current constitutions of so many sub-Saharan African countries. Nowhere in this great panoply of human rights provisions is it once asserted that it is the grandmothers of the world who have the responsibility to deliver rights to the people. Quite the opposite. Because of their special vulnerabilities, grandmothers are entitled to enhanced protection to ensure they can enjoy their own rights, and lead decent, secure lives.

Grandmothers' human rights are being doubly violated. First, of course, because they themselves are not being protected as they should be from extreme poverty, hunger and homelessness. But also second, and more insidiously, because they have been left to meet the burden of the State's proper responsibilities for the children and vulnerable people in their communities though their own unpaid labour.

When the HIV and AIDS pandemic first struck sub-Saharan Africa, it might have been possible to forgive or at least understand this abdication. Many of the social support structures that are now so clearly needed had not been put in place by governments, not just because of limited resources, but because of the assumption that local communities could provide sufficiently for themselves. Perhaps they once could. But the evidence now is quite overwhelming that HIV and AIDS has set off a social protection crisis, and that Africa's grandmothers are shouldering an unconscionable burden as they try to fill the gap. The members of the international community, donors and governments who treat social protection as a secondary, add-on, consideration to the mainstream HIV and AIDS response can't claim ignorance anymore: they are being willfully blind. Even more troubling is the almost unavoidable conclusion that discrimination against women is clouding the policy vision, so that the exploitation of women through unpaid care work seems unproblematic, and the personal fates of women, especially older women, are of marginal concern.

There are four measures that must be urgently undertaken to protect the economic rights of grandmothers, and the rights of the children who depend on them.

First, pensions or cash transfers must be granted to grandmothers, at a level that is sufficient to cover the costs of their essential needs, and the needs of the children they are caring for. A number of countries in sub-Saharan Africa already have pension schemes in place to support older women. These should continue, and should be extended to as many new countries as possible. But further attention should be paid to the amount of income they are providing, as it is not always enough to keep grandmothers out of poverty. And attention also needs to be paid to the age at which pensions are conferred. As one of the grandmothers explained today, women can find themselves in the position of being the sole support for their grandchildren at a much earlier age than 60, and they have an immediate need for funds to help them care for their families. There are of course many countries which, at present, may not be able to manage the financial and administrative costs of implementing universal pension plans for all of their older citizens. In such cases, cash transfers to grandmothers caring for children are the recommended route. Numerous studies have found that targeted cash transfers are the most efficient and effective way to provide for the needs of vulnerable groups of people in countries that face financial constraints. Furthermore, a consensus has emerged from the experience of implementing cash transfer schemes in a number of countries, that the best way to ensure that funds will ultimately be spent on the most important family needs is to allocate them directly to the women who take responsibility for caring for the children.

Second, much more investment is needed to expand economic opportunities for grandmothers. We need to be careful when talking about grandmothers' economic self-sufficiency, as the category of "grandmothers" encompasses many different women. Some of them are still in the prime of their lives, while others are quite elderly and should not be expected to fend for themselves. But certainly, for the younger grandmothers, developing the skills and acquiring the resources that will enable them to generate all the income they need for themselves and their families is far preferable to having to rely on the—always limited—support provided by others. The grandmothers have told us today about the really encouraging turns their lives took once they had land, seeds and fertilizer sufficient to grow crops both for food and for sale, how a few cows can multiply to support a whole family, and how learning the right skills and trades has made it possible for them to work from their homes. And when expanding support for the grandmothers' economic empowerment, we must look seriously at what does and does not work in the context of the HIV and AIDS pandemic. For example, micro-credit, which is often touted unreflectively as some sort of "miracle cure" for poor people, can have really problematic effects. While the sums of money involved are small, it is still essentially a debt mechanism. A grandmother who isn't able to repay one of her loans can find herself unable to meet the costs of accessing HIV and AIDS treatment, struggling again to feed her children, even taking them out of school, and the shame of failing to pay her debts may pull her back into isolation from the community.

The failure to remunerate caregiving work—a type of work that for so long has been considered "only" women's work—is actually a form of structural discrimination, which deepens grandmothers' poverty and compromises their ability to care for their own health.

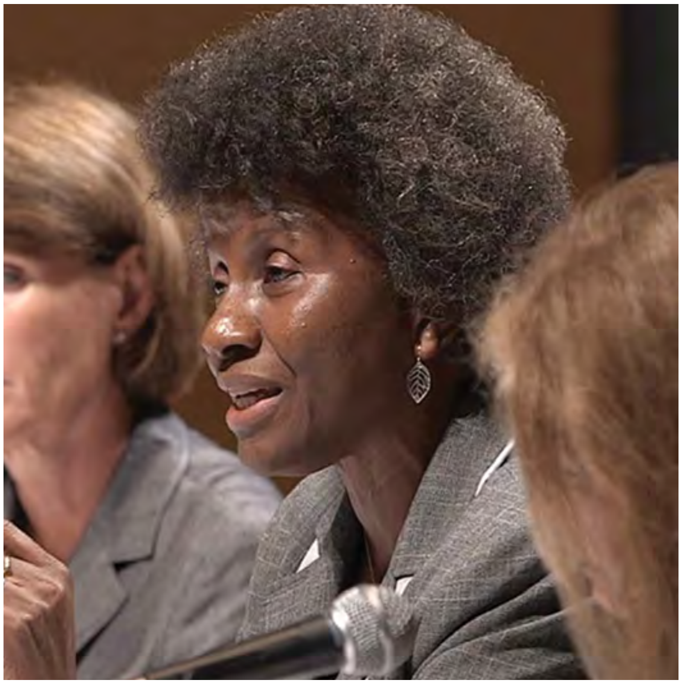
Third, many grandmothers have taken leading roles in caring for vulnerable members of their communities.

Every grandmother who has spoken to us today is investing her precious energy, not just in supporting her own family, but in making sure that the lives of other grandmothers like herself improve, feeding and tending to the needs of neighbourhood children, working to ensure that women's right to live free from violence and rights to land and housing are protected, and making sure that people living with HIV and AIDS get the counselling and support they need to access treatment. Only rarely do they get compensated for any of their efforts. In recent years, the international community has started recognizing just how effective this sort of community-based care is in mitigating the impact of the pandemic, and helping to extend healthcare to more people. More plans and policies are integrating community health workers and "secondary caregivers" into programmes for expanding the reach of the HIV and AIDS response. This is commendable, but there is a serious danger that gender-based discrimination will distort things. Grandmothers' free labour should not be seen as the solution that will make up for limited government or donor funds, and relieve them of their responsibilities. We must be very clear that the failure to remunerate caregiving work—a type of work that for so long has been considered "only" women's work—is actually a form of structural discrimination against women, which deepens their poverty and compromises their ability to care for their own health. All community care workers, and especially the grandmothers, must be compensated.

Any serious long-term vision for the countries that have been hit hardest by the pandemic must include free secondary school for all.

Finally—how to keep the children in school? That's one of the questions that weighs heaviest on the grandmothers' minds. In households with such precarious incomes, there almost always comes a time, if not during primary school then certainly in secondary school, when the money runs out and the children's education has to come to an end. Grandmothers try to do everything in their power to prevent this, because, as we were told today, their hopes for decent futures for their grandchildren depend on them completing secondary school. Despite the fact that human rights law clearly requires governments to ensure all children can complete primary school, ancillary fees for uniforms, books and other materials are shutting the poorest children out. These costs must be abolished. The financial challenge of paying tuition for secondary school is even greater, and while assistance is sometimes given to help vulnerable groups of children, it falls far short of what's needed. Schemes that are intended to target assistance specifically to HIV and AIDS orphans have proven difficult to operate effectively. Furthermore, they can introduce tension and conflict into communities in which so many other poor children can't afford to stay in school. The grandmothers are quite right. Secondary school is a make or break issue for the future, not just for their own grandchildren, but for all of the children. Any serious long-term vision for the countries that have been hit hardest by the pandemic must include free secondary school for all.

NEAL HICKS/SLF



Joy Phumaphi

Executive Secretary,
African Leaders Malaria Alliance

The HIV and AIDS pandemic has changed. It is not what we were facing twenty or even ten years ago, when, as the grandmothers have told us, all one could do was sit hopelessly at the bedsides of family members, caring for them until their inevitable deaths. The rates of new infections in sub-Saharan Africa have been steadily decreasing. There's been a dramatic increase in the the antiretroviral (ARV) treatment that can enable them to live much longer, healthier lives with the disease. While the statistical measures may vary, there is no dispute that there's been a significant decrease in the number of deaths caused annually by HIV and AIDS. Over the last few years a global recognition that treatment is prevention has emerged, and a global consensus has been reached that universal access to treatment could be the solution for HIV and AIDS, if the political will and financial commitment is strong enough.

"Treatment" is now the magic word on the policy makers' lips. But a serious response, one that genuinely respects the human right to health of every person living with HIV and AIDS, needs to pay close attention to who is and is not receiving treatment, and why. Despite the gains that we have seen, it remains true that AIDS is still the leading cause of death around the world for women between 15 and 49 years of age, and in sub-Saharan Africa almost 60% of the adults living with HIV are women. Studies have indeed shown that women living with HIV who are eligible to receive ARV treatment are—on average—more likely to obtain treatment than eligible men. However, the situations of different groups of women vary greatly, and the heightened attention that has been given to women of childbearing age, and the targeted testing and treatment that is available through maternal and child health services and antenatal clinics, does not extend to all women.

Stigma and discrimination are still definitely at the heart of the problem.

The grandmothers have told us today of how difficult it can be for them to get the testing and treatment they need. Violence and the fear of violence from their husbands and family members not only exposes grandmothers to infection, but can also intimidate them from getting tested. Once they do know their status, there can be a high price to be paid for disclosure, in the form of physical assault, divorce, abandonment, and homelessness. Seeking treatment from public hospitals and clinics can seem too dangerous for older women who know that their immediate safety depends on secrecy. Long distance travel for treatment may be too physically demanding for older women whose health is fragile.

Where there are costs associated with treatment, no matter how modest, grandmothers can be shut out—as we have heard today, their budgets are stretched to the breaking point trying to care for themselves and their grandchildren, and the first sacrifice they're willing to consider is usually their own well-being. And while proper nutrition is absolutely essential to ensure that the treatment they do receive will be effective and lead to improved health, grandmothers frequently lack the income and the knowledge they need to maintain nutritious diets. The grandmothers who have become overwhelmed, isolated or depressed because of their situations can also have trouble finding the stamina to keep on track, and maintain their treatment over time.

As the grandmothers' testimonies have shown us, stigma and discrimination are still definitely at the heart of the problem. Greater familiarity with the disease may have lessened the extremes of communities' rejection and reactions, but people continue to have reason to fear and avoid the disclosure of their HIV status. Even where anti-discrimination laws are in place, employers will find ways to keep HIV-positive people out of their workforces. Hospitals admit patients with HIV and AIDS, but insist on their segregation. People living with HIV continue to be seen as "those people", not "part of us", and denial is rampant among those who are diagnosed as positive. There's still not enough acceptance and understanding of HIV and AIDS as a disease like any other. People continue to think of HIV as a death sentence, and in their fear and ignorance they reject the very life-saving, life-extending testing and treatment they need.

I have mentioned that the global community is readying itself for a renewed and intensified focus on treatment, in light of the evidence proving that early and continuous treatment can significantly reduce the likelihood that an HIV-positive person will infect others. In the absence of a vaccine, treatment appears to be the best available path to stop the spread of the virus, and end the pandemic. The case was made most recently by UNAIDS, in its July 2013 publication "Treatment 2015".

The new direction UNAIDS charts, which also reflects much of what can be found in PEPFAR's 2012 "Blueprint for an AIDS-Free Generation", is quite encouraging overall. They advise that countries should prioritize efforts to ensure that all people eligible for HIV treatment have access to it. They note that the people who have not yet received HIV testing and treatment belong to groups who are the most difficult to reach, so that new and additional measures will be needed to expand the scope of HIV-related healthcare. Treatment systems should therefore be adjusted to the needs and circumstances of the people that use them. Programmes should focus on the populations and settings in which the need for HIV treatment is most acute, and countries should establish targets for these "key" populations.

Social and legal impediments that prevent these populations from accessing testing and treatment should be removed. Because community engagement in service planning and delivery is recognized as particularly important for people who face challenges accessing services through mainstream health systems, greater healthcare investment is recommended at the community level. Furthermore, stronger leadership roles for members of key populations are advised in the design and operation of community services.

> ***We have to keep insisting on priority attention for all of the groups of people whose rights to health are being poorly met by healthcare systems—including the grandmothers.***

However, one note for concern, or at least for our care and watchfulness, is the manner in which the category of "key populations" is being addressed in the current discussions. There is a tendency to speak about the groups of people who have difficulty accessing treatment, and the groups of people whose infections are major contributors to the spread of the disease, as if they were one in the same when they clearly are not. Discrimination and marginalization are making it harder for both grandmothers and, say for example, men who have sex with men, to access healthcare. But positive grandmothers don't play a statistically important role in the spread of HIV. The fundamental human rights principle that all people are entitled to treatment can't be overshadowed or replaced by the tactical insight that treating certain populations is especially effective for slowing the spread of HIV and AIDS. Better treatment delivery to some populations—such as men who have sex with men, people who inject drugs, and sex workers—certainly can play a crucial role in reducing the spread of the disease. But we have to keep insisting that they deserve enhanced treatment efforts in their own right, as human beings who have been marginalized by healthcare systems through discrimination and inequality, not just because they are helpful tools or instruments for fighting AIDS. And, equally, we have to keep insisting on priority attention for all of the groups of people whose rights to health are being poorly met by healthcare systems—including the grandmothers—regardless of their "strategic" value.

We're at an important crossroad in the response to the HIV and AIDS pandemic. On one hand, with the discovery of treatment's effectiveness for prevention, the possibility of reaching zero new infections actually seems to be in reach. On the other hand, financial constraints and donor exhaustion make future funding uncertain, and are placing a premium on targeted, shorter term investments. It's the right time to be seriously reflecting on what the HIV and AIDS response really needs to achieve. HIV and AIDS is a medical emergency only in the most immediate sense. At a deeper level it is a profound development challenge, and a human rights crisis for the people and communities infected and affected by the disease.

Our goal must be the restored health and well-being of the people who live in countries hardest hit by HIV and AIDS, and the promise of decent futures they can work together to build.

The endpoint of the response can't simply be seen as zero new infections. Our goal must be the restored health and well-being of the people who live in countries hardest hit by HIV and AIDS, and the promise of decent futures they can work together to build. From this perspective, what happens to the grandmothers in sub-Saharan Africa matters hugely, and taking measures to ensure they receive proper treatment and continue to lead healthy, productive lives is an absolute priority. The grandmothers stepped in, with love, to shoulder the burden of children orphaned by AIDS when there was no other help to be found. Grandmothers are now supporting and caring for a significant percentage of sub-Saharan Africa's next generation. Their continued well-being is necessary.

The following measures are required to protect and advance the human rights of grandmothers in the medical response to the HIV and AIDS pandemic.

First, a better information base is needed. General statistics and averages don't tell us what we need to know in order to ensure that the rights of grandmothers to access healthcare are being respected. As efforts intensify to extend treatment to more people, we must insist, not only on gender disaggregated data about the recipients, but also on data that is disaggregated by age, family structure and income.

Grandmothers should be included as one of the target populations when countries develop their national plans to scale up access to HIV treatment, and grandmothers should be included on the advisory bodies that design and oversee the implementation of these plans.

Community-level programmes must be developed that specifically address the challenges older women face in accessing treatment, and the best way to ensure this is to bring grandmothers and their representatives to the table from the very beginning, when programmes are being designed.

All out-of-pocket costs for HIV testing and treatment should be eliminated, so that financial constraints stop limiting access to treatment.

Grandmothers who are currently working on a volunteer basis with grassroots NGOs in their communities to provide care, counselling and support to people living with HIV should be paid for their labour.

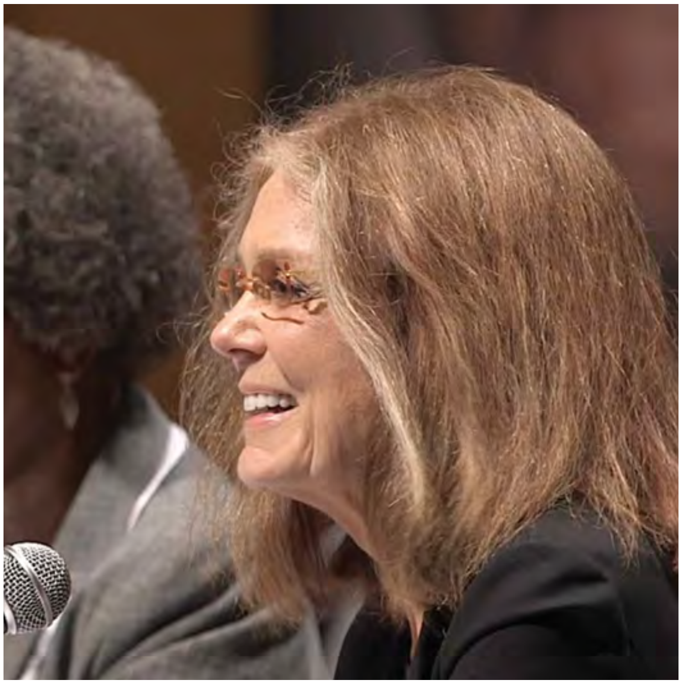
As treatment is expanded, grandmothers should continue to be consulted and employed, as community healthcare workers and as expert patients, to help ensure that the follow-up and support services needed to keep older women in treatment are working effectively.

Grandmothers' leadership is also needed in community-based efforts to broaden awareness about the availability of simple, easily tolerated treatment regimes, and user-friendly testing options, to bring more older women into treatment.

Policy frameworks should prohibit discrimination against people living with HIV and AIDS, and countries should take action to reduce discrimination in healthcare settings.

Anti-stigma campaigns should be undertaken, not just with the support of local community and religious leaders, but also with strong commitment from heads of State and other prominent national figures.

Finally, as global commitments are being made, and national goals and targets are being set to begin an intensified push to extend the reach of treatment, we must continuously insist on the human right to HIV and AIDS treatment for everyone.



NEAL HICKS/SLF

Gloria Steinem

Feminist Activist and Author

Dear Friends, Activists, Sisters, Brothers, and most of all, Grandmothers—our heroes and our teachers:

I've been invited here as a witness and a judge today, and even before meeting you, I had the privilege of reading your stories. You have braved daily disasters and deprivation, you yourselves have had too little love and help from those around you, yet you have loved and helped children and many others around you. Each one of you is a unique miracle. No one on earth could hear any one of your unique stories without being awed and inspired.

I would like to add three ways that I believe you are crucial even beyond what you yourselves may encounter every day.

First, you as grandmothers are teaching and inspiring through stories—and stories are almost as crucial to human beings as air, water and food.

We as humans have been formed by sitting around campfires for at least 100,000 years, each one sharing our unique experience in the narrative and imagery of story. That's how we conveyed knowledge, from birthing and the stages of life to maps, weather, healing, astronomy, animal behaviour, the power of the mind over the body—everything. Even now, if you tell me a fact or statistic, I will make up a story to explain why it is so.

> *Grandmothers are teaching and inspiring through stories—and stories are almost as crucial to human beings as air, water and food.*

Yet our modern media and educators don't always understand that our brains are organized by narrative and image. Instead, they give us generalities and statistics and words that end in – tion. This is another price we pay for the falsity of gender. Facts and statistics are considered "hard news," serious scholarship and "masculine," while narrative and image are considered "soft news," trivial, and "feminine."

This leaves us hungry for understanding through story. It leaves us feeling outside media and communities of learning—and makes us vulnerable to everything from celebrity journalism to dictators and religions—to anything or anyone that offers narrative and imagery and story—even when our instincts whisper to us that their stories are manipulative and false, that they divide us from each other.

Perhaps I should say here that I'm making a distinction between religion and spirituality, between a hierarchy that ranks us—men over women, humans over nature—and a circle that links us—males and females and all living things. I know we may use different words in our different languages. So perhaps I should just say about telling the difference between true and deceptive story: Trust your instinct. Honour that which honours your story and allows you to honour others. You wouldn't have survived or helped others to survive if you hadn't followed your deepest instincts. As a friend from Kenya once said to me: *If it looks like a duck and quacks like a duck and walks like a duck, but you think it's a pig—it's a pig!*

Second, you have already discovered through the crucible of HIV and AIDS that sharing our stories is how we know we are neither at fault nor alone. In my country, the oldest cultures say of someone who is ill or destructive, "They have lost their story... they have lost their own song." Sharing stories and acting on their common themes is the source of every social justice movement I know. In a way, the tragedy of HIV and AIDS may have forced you to learn and to teach this wisdom that everyone needs in all areas of life.

Third, what has made HIV and AIDS even more of a danger to females than to males is far more than a minor difference in physiology that makes men less vulnerable through external skin, and women more vulnerable through internal membrane. It is a major difference in power between males and females in every area of life, from culture to politics. It is deep and definitional. What happens to men is called politics. What happens to women is called culture. Men's work is included in economics and measured in money. Women's work is often invisible and not measured at all. And this profound structural inequality gives women little choice in sexual relations, even when their decision would be an act of self-preservation.

This makes you the shock troops, the early warning system, the prophets of violence against females and its cost on this spaceship Earth that we all share.

I believe we all have instinctive knowledge of violence against females as basic to all other violence, but now it has been proven. In *Sex and World Peace*—a book by Valerie Hudson and three other international scholars—100 current countries, with many different governance systems, were assessed. Here is the conclusion: The single greatest determinant of whether a country is violent within itself—or will use military violence against another country—is not poverty, or natural resources, or religion, or even the degree of democracy. It is violence against females.

In some countries, female infanticide has produced a daughter deficit and a son surplus. For the first time in history that I know of, females are no longer half the human race. In many countries, child marriage and forced impregnation and childbirth have produced a human population that cannot be sustained. In my country, more women have been murdered by their husbands or boyfriends since 9/11 than Americans were killed in 9/11, both Iraq wars and the war in Afghanistan—combined.

Female life is not more valuable than male life. One can also imagine males being vulnerable, especially since their unprotected genitals are on the outside. The problem is making one group of people powerful over another by dividing human beings into gender prisons of "masculine" and "feminine," the leaders and the led, those who own property and those who don't or even are property, those who own children in marriage and those who do the work of raising them—all of this inequality requires violence to maintain.

And it is that violence that normalizes all other violence, and that false division of gender roles that normalizes roles and violence based on race, caste, class, tribe, nation or culture.

What has made HIV and AIDS even more of a danger to females than to males is far more than a minor difference in physiology, it is a major difference in power between males and females in every area of life.

It wasn't always like this. Most of human history on all our continents seems to have been matrilineal. Many Native Canadian and Native American cultures didn't even have "he" and "she" in the language, much less did attribute gender to tables and chairs. For reasons I think I understand, Europeans became the inventors of patriarchy, in turn became over-populated, and invaded my continent and yours. Much of why they called cultures "primitive" was because women had equal power and controlled reproduction.

Because controlling reproduction—controlling female bodies—is the root and rationale of male supremacy. Without it, racism and other birth-based hierarchies can't continue into the future without controlling reproduction. Thus the bodily integrity of females is also the answer not only to slowing the spread of HIV and AIDS, but to a population growth that slows and becomes sustainable, to ending the divisions of clan and race and caste—and for females ourselves, to an end to forced pregnancy, female genital cutting, infibulations, sex trafficking, survival sex—an end to the basic division that normalizes violence.

So you who are raising the children of the lost—you are teaching by your lives and by your stories.

Perhaps in the future, historians will look back and say: This is when humans re-discovered that we are linked, not ranked. This is when a lethal illness forced females to rebel, and males to find their humanity in those who rescued them. This was the time of the grandmothers.

Cathie Archbould

Grandmothers' Call to Action

We recognize and endorse the judges' statements and recommendations.

They are a true reflection of our concerns and the measures that urgently need to be taken.

Above all what we find true in what the judges have said is that the time has come.

It's time to recognize that grandmothers at the forefront of the HIV and AIDS crisis must have our human rights respected and protected.

It's time to support our organizations fully, and put systems in place to address our needs and the needs of the children in our care.

It's time to recognize our contribution to the survival of our communities, and the expertise we have developed to do so, by giving us our rightful place and voice wherever decisions are being made.

We, the grandmothers of Africa, speak to you now as the guardians of the future.

Our labour, with all of its struggles, challenges, knowledge, and triumphs, has gone unheeded for too long.

We will not let the AIDS pandemic defeat us, nor destroy our communities, but we cannot prevail alone.

Africa cannot survive without us.

We call on you to act with urgency and purpose to support our efforts to secure justice.

It is time!

Stephen Lewis Foundation Statement of Commitment

Ilana Landsberg-Lewis, Executive Director

Friends, Judges, Grandmothers …

We have heard your voices, and I know all of us feel the searing sting of injustice, the agony of loss, and the profound determination, strength and love that you have brought to meet the ravages of AIDS in your families and communities.

The tenacity and intelligence of your responses to the scourge of AIDS are breathtaking, and I could not be prouder in this moment to stand here with you as a witness and a passionate ally in the struggle.

We know that you speak for millions of grandmothers and the organizations supporting them. We understand that this is not an exercise in charity or benevolence. The threshold of tolerance for injustice must be shattered today, and the resources and support you require to effect change in the face of AIDS—whether it is pensions, access to healthcare, or to be consulted and counted in the responses to the pandemic—must be acted upon.

We will take up your call to action and the recommendations of the judges, and we will not rest until the world comes to its senses and the support that should and must come is yours.

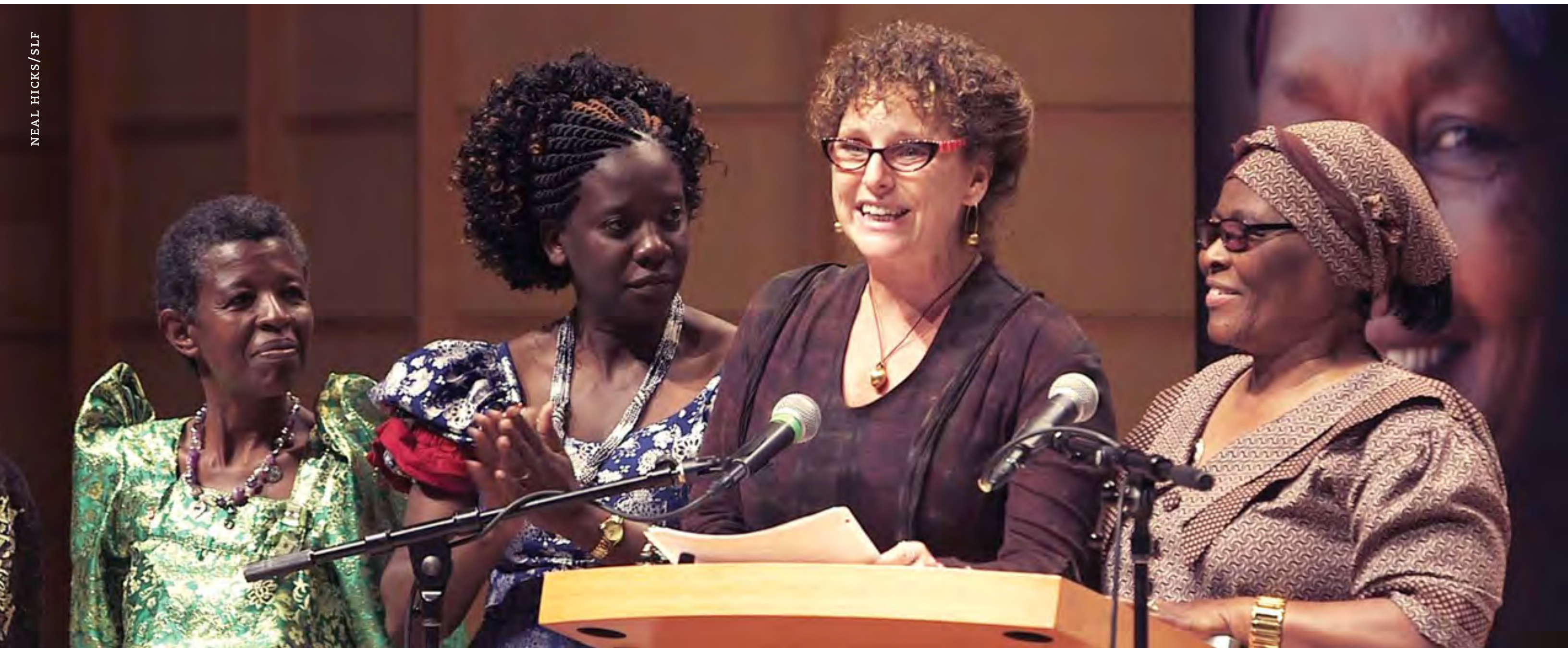
You have given us a clear agenda for support— whether it's a global fund for cash transfers, the need for national level advocacy, the continuing urgency for land rights and housing, access to healthcare, universal and accessible education, food security, and laws protecting grandmothers from violence and the means to enforce them.

Today we commit to you anew.

All of us at the Stephen Lewis Foundation—and I know the Canadian Grandmothers are with us—will not rest until you have the justice you demand.

We commit to redoubling our efforts and to bend every fibre of our collective beings to break the inertia, the silence, and the dam of neglect and negligence that prevents the flood of resources from flowing.

We will be accountable to you, and heed you, as must now the world.



NEAL HICKS/SLF

Cathie Archbould

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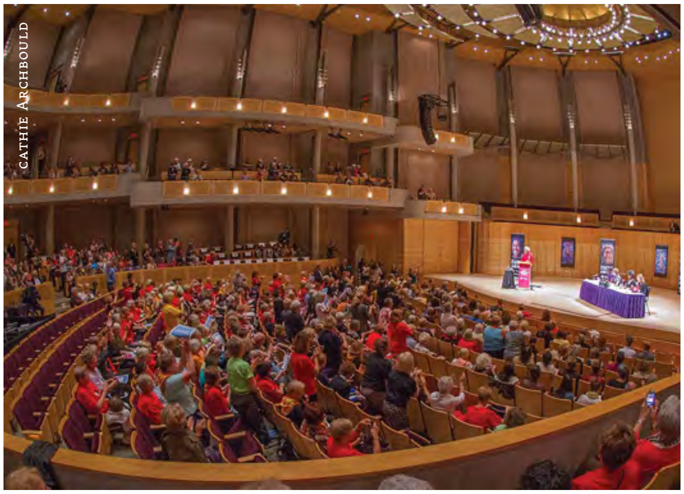
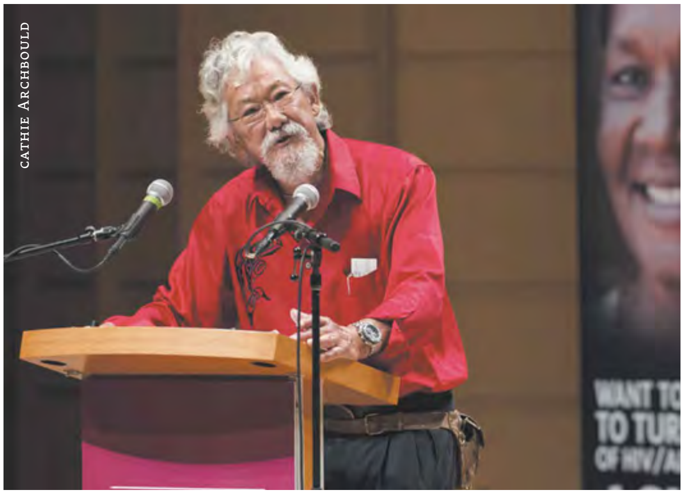


Cathie Archbould



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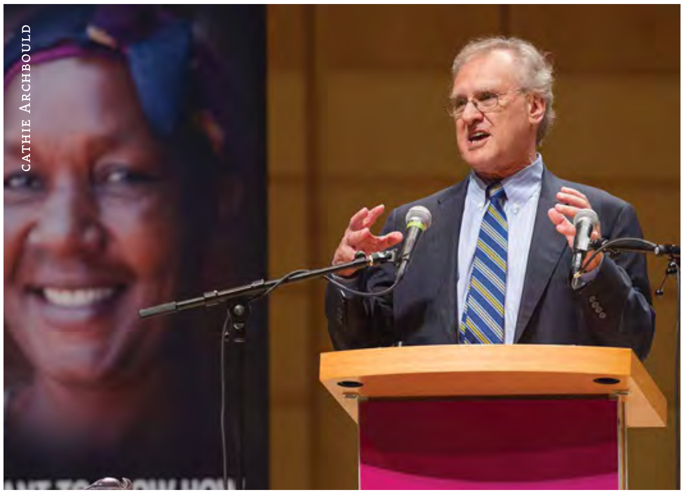


Cathie Archbould

Programme of Events — African Grandmothers Tribunal

September 7, 2013, Chan Centre at UBC, Vancouver, BC

Event moderated by Patsy George

9:55–10:00	Grandmothers Campaign members welcome
10:00–10:30	Welcome by David Suzuki, opening remarks by Stephen Lewis
10:30–10:45	Testimony 1: Thulisile Dladla
10:50–11:05	Testimony 2: Immaculate Nakyanzi
11:10–11:25	Testimony 3: Mama F
11:30–11:45	Expert Testimony 1: Robina Ssentongo
11:50–12:00	Performance by d'bi.young anitafrika
12:00–1:00	Lunch
1:00–1:15	Testimony 4: Zodwa Hilda Ndlovu
1:20–1:35	Testimony 5: Magret Ongwen
1:40–1:55	Testimony 6: Mariam Mulindwa
2:00–2:15	Expert Testimony 2: Siphiwe Hlophe
2:15–2:45	Break
2:45–3:45	Judges' Recommendations
3:50–4:10	Closing remarks and call to action by Ilana Landsberg-Lewis and African grandmothers

Profiles

Testifying Grandmothers

Thulisile Dladla

Manzini Region, Swaziland

Thulisile is a dynamic and tireless advocate for the orphaned children in her community. This passion prompted her to join SWAPOL in 2001, and soon thereafter to become a board member. Thulisile runs a feeding programme for vulnerable children from her home, and goes out into the community as a trained caregiver to visit terminally ill community members. Thulisile is a grandmother living with HIV, who has lost many family members to AIDS, and is dedicated to supporting orphaned children—a lynchpin for survival of her community and its future.

Immaculate Nakyanzi

Kkingo Subcounty, Uganda

Immaculate worked hard to reclaim the strength and spirit to support her family and others in need in her community. She lost many family members—children, brothers, sisters, and her husband—to AIDS, and assumed the care for multiple grandchildren. With the support of Kitovu Mobile, Immaculate started a project to cultivate maize and beans to generate income. It has been a long journey, but Immaculate is a survivor, and an example to others of the triumph of the human spirit over adversity.

Mama F *

Zimbabwe

Mama F is a stoic and inspiring hero, and a grandmother living with HIV. She was a nurse's aid and a pharmacy assistant, who had a long battle trying to stand up to her abusive husband with no support from local authorities. When her husband divorced her she discovered Chiedza—a community project that came to provide her over time with psychosocial support, skills, school fees, clothing, and food for the four orphaned children in her care. Mama F now volunteers at Chiedza—her "second home," working with families in her community to fight the stigma associated with HIV and AIDS, encouraging everyone to get tested and teaching people how to live positively and women to live free from violence.

** We have withheld this grandmother's name to protect her safety—speaking out about human rights in Zimbabwe at this time may pose a risk.*

Zodwa Hilda Ndlovu

Durban, South Africa

Mama Zodwa is a grandmother and retired nurse. She is also a pillar of strength and an indefatigable force for good and survival in her community. Zodwa lost both of her children to AIDS in a heartbreaking series of events, and is HIV-positive herself, proudly living positively and openly—encouraging dialogue in her community and facilitating the healing conversations in other families affected by HIV and AIDS that she didn't get to have with her own children. Mama Zodwa runs a small soup kitchen for children orphaned by AIDS to visit before going to school, and runs an organization which engages in AIDS education, home-based care, and treatment adherence. She is devoted to ensuring that no one affected or infected has to live with stigma or the silence that goes with it, be infected because of lack of knowledge, or lose hope because there is no help or succor nearby. She is a beacon of light for so many.

Magret Ongwen

Nyanza Region, Kenya

Magret is the personification of courage. She refused to be inherited by another man when her husband and co-wives died of AIDS and left her with 6 orphaned children. She knew being inherited would expose her to HIV infection, and she had already protected herself at great personal cost. Magret has received strong support from PENAF and has become a role model to the women in her community. She is now the assistant chairperson of PENAF's Uloma group, which has a membership of 200 grandmothers. A grandmother of deep conviction and resilience, she is a revolutionary agent of change.

Mariam Mulindwa

Jinja District, Uganda

Mariam is an irrepressible leader and motivator in her community. She lost many family members to AIDS, and is the full-time caregiver for 24 orphaned and vulnerable children. In 2003 Mariam joined PEFO, and quickly became a mobilizer and inspiration for other grandmothers, coordinating World Health Day celebrations, and representing older persons on the Sub-County Land Rights Committee. In 2011 she was voted Ms. Granny for Eastern Uganda—bringing visibility and authority to the role of grandmothers.

Expert Witnesses

Robina Ssentongo

Director, Kitovu Mobile AIDS Organization, Uganda

Robina Ssentongo has worked with Kitovu Mobile since 1988. She originally joined the organization as a Nurse Counsellor, providing home-based care and support to AIDS patients. From 1990–1994 she served as the Coordinator of the Orphans and Family Support programmes, and she now oversees all operational and programmatic work, leading a team of 85 staff and 760 community workers and volunteers. Previous to her work with Kitovu Mobile, she worked as a midwife at Rubaga Hospital in Kampala, Uganda. A skilled facilitator and programme designer, Robina holds a Masters Degree in Health Services Management from Uganda Martyrs University and an undergraduate degree in Community Development from the University of South Africa.

Siphiwe Hlophe

Founder and Director, Swaziland Positive Living (SWAPOL)

Siphiwe Hlophe was one of the first women in Swaziland to publicly declare her HIV-positive status, and remains one of the country's most prominent HIV and AIDS activists. In 2001, Siphiwe and four other HIV-positive women started SWAPOL. She has served on Swaziland's National Emergency Response Committee on HIV and AIDS, and has been the Chairperson of the International Community of Women Living with HIV and AIDS in Swaziland and a member of the UN Secretary General's Task Force on Women, Girls and HIV and AIDS in Southern Africa. Siphiwe was the recipient of the 2006 African Women's Development Fund's Stephen Lewis Fighting Spirit Award and the 2007 Index on Censorship's Freedom of Expression award, and she is featured in Stephanie Nolen's book *28: Stories of AIDS in Africa.*

Judges

Gloria Steinem

"Gloria Steinem has long been the voice of North American feminism, inspiring women across the globe with her wit, her generosity of vision, her tireless activism and inclusion of women from all walks of life. She has given us the gift of her brilliant insights and the memorable words with which to frame them—and has given voice to a movement that changed the world. She is not only a founder of *Ms.* Magazine and the author of many bestsellers, but is also an activist leader who has co-founded and worked with numerous critical feminist organizations, from Voters for Choice to the Ms. Foundation."

— Michele Landsberg, Columnist, Author and leading Canadian feminist

Joy Phumaphi

Joy Phumaphi is a recognized leader in global health and human development. She is the Executive Secretary of the African Leaders Malaria Alliance (ALMA). Previously, she held the positions of Vice President and Head of the Human Development Network at the World Bank, Assistant Director-General for Family and Community Health Department at the World Health Organization, and Minister of Health of Botswana. Joy Phumaphi is a distinguished African American Institute Fellow. She has been a Commissioner in the UN Secretary General's Commission on HIV and AIDS and Governance in Africa and chaired the steering committee for the 5-year evaluation of UNITAID. Joy Phumaphi co-chairs the independent Expert Review Group for Every Woman Every Child and chairs the Botswana African Comprehensive HIV and AIDS Partnerships. She is a board member of the Mo Ibrahim Index Advisory Council, the Aspen Institute Global Leaders Council for Reproductive Health, and the Lephoi Centre in Botswana. She is also a board member of the Al Gore Foundation, and a trustee of the Children's Investment Fund Foundation.

Mary Ellen Turpel-Lafond

Mary Ellen Turpel-Lafond is respected as a champion for the voices and rights of vulnerable children and youth. Her passion and effectiveness were recognized in 2006 when she was appointed BC's first Representative for Children and Youth, as an independent officer of the Legislature. Ms. Turpel-Lafond is on leave from the Saskatchewan Provincial Court where she worked as a criminal law judge in youth and adult courts. In 2007 the Indigenous Bar Association awarded her the distinction of Indigenous Peoples' Counsel. She has twice been named one of *Time* Magazine's '100 Global Leaders of Tomorrow'. Ms. Turpel-Lafond is an active member of Saskatchewan's Muskeg Lake Cree nation.

Theo Sowa

Theo Sowa is the CEO of the African Women's Development Fund. She has extensive experience as an independent advisor on a wide range of international and social development issues. Her work on women's rights has a special focus on their promotion and protection in armed conflict situations, the strengthening of women-focused development programmes in Africa, and advocacy related to women and HIV and AIDS issues. She is a member of Stephen Lewis Foundation's African Advisory Board and the board of the Graça Machel Trust. She also serves on the board of the Museum of AIDS in Africa; is a Trustee of Comic Relief and the Chair of its International Grant Making Committee; and is an Advisory Group member of the 'Every Child a Reader' literacy initiative. She holds a public appointment as a board member of the Charity Commission for England and Wales and was awarded a CBE in 2010.

Projects

Swaziland Positive Living

Swaziland

Swaziland Positive Living (SWAPOL) was the first organization in Swaziland to address the needs of people living with HIV and AIDS. They work primarily with women, orphans, and child-headed households, with the understanding that these groups have suffered the most as the result of the pandemic. SWAPOL provides home-based care delivered through a mobile clinic and individual caregivers, supports child education and development, supports greater food security and nutrition through community training and the provision of seeds for community gardens, conducts livelihood projects, provides psychosocial counselling, and advocates against property grabbing.

Kitovu Mobile AIDS Organization

Uganda

Kitovu Mobile AIDS Organization (Kitovu Mobile) focuses on supporting people living with and affected by HIV and AIDS in their communities, enabling them to cope with its impact, and improve their quality of life. Kitovu Mobile works with its network of more than 750 volunteer community workers to provide care, support, prevention and capacity-building to poor rural communities with high rates of HIV and AIDS. Their programmes span a broad range of support, including: home-based care for people living with AIDS, grandmothers support, child protection and education, housing support, psychosocial support, self-help groups for women, and education for HIV and AIDS prevention and management.

Chiedza Child Care Centre

Zimbabwe

Chiedza Child Care Centre (Chiedza) works with children affected and infected by HIV and AIDS in crowded urban areas. The organization provides children with a safe haven, and helps them access education, health, recreation, nutrition and psychosocial support. Chiedza runs a community home-based care programme for vulnerable and orphaned children, which is focused on meeting their caregivers' immediate needs and empowering them through income-generating activities. Chiedza also runs a grandmothers' support group of 15 tight-knit grandmothers, who refer to each other as "sisters."

Siyaphambili

South Africa

Siyaphambili is a support organization for people living with HIV and AIDS. They support orphans and vulnerable children living with grandparents; provide counselling and education on living positively with the virus; and work to encourage testing and to counter stigma and discrimination. Their mission is to decrease the number of new infections and to encourage those infected and affected by HIV to seek support, share their experiences and lessons, cope, and even thrive.

Pendeza Africa

Kenya

Pendeza Africa (PENAF) is helping the grandmothers and youth of western Kenya combat the impact of AIDS in their local villages. The organization supports a wide range of community development and emergency relief initiatives, with a primary focus on women's empowerment, orphan support, youth life skills training, revolving credit schemes and environmental protection. Since its inception in 2004, PENAF has been providing support for small scale entrepreneurship to vulnerable women and grandmothers, providing them with much needed income, and enabling them to provide for the children in their care and increase their self-esteem and confidence.

Phoebe Education Fund for AIDS Orphans and Vulnerable Children

Uganda

Phoebe Education Fund for AIDS Orphans and Vulnerable Children (PEFO) is dedicated to improving the welfare of grandmothers and children affected by HIV and AIDS in eastern and central Uganda. PEFO helps to send orphans to school, ensures families have adequate nutrition, encourages income-generating activities for caregivers, builds new houses for vulnerable rural grandmothers, and assists with health care and psychological counselling access. The organization helps orphans, vulnerable children, and their caregivers to achieve the self-esteem and self-reliance they need to become a resource for themselves and their communities.

Moderator

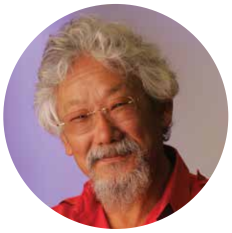
Patsy George

Member of the Board,
Stephen Lewis Foundation

Patsy George has fostered innovation and social change in communities across British Columbia and Canada for more than 50 years. She retired from public service in 2001, and her work in public welfare, child welfare, and community development—including as Director of Multiculturalism and Immigrant and Settlement Services BC. A few of the achievements of her long and illustrious career include organizing the Solidarity Coalition, working with the BC Federation of Labour to fight government cutbacks, serving on the Immigration and Refugee Board of Canada, and acting as a member of the Community Panel to Review Family and Children's Services Legislation in British Columbia.

Presenters

David Suzuki



Co-founder, David Suzuki Foundation

Dr. David Suzuki is a renowned scientist, broadcaster, and author. He is Companion to the Order of Canada, a recipient of UNESCO's Kalinga Prize for science, the UN Environment Program medal, the 2012 Inamori Ethics Prize, and UNEP's Global 500. Dr. Suzuki is Professor Emeritus at UBC and holds 28 honorary degrees. He is known to TV audiences as host of the CBC science and natural history series *The Nature of Things*, and to radio audiences as the original host of CBC Radio's *Quirks and Quarks* and the acclaimed series *It's a Matter of Survival* and *From Naked Ape to Superspecies*. In 1990 he co-founded, with Dr. Tara Cullis, The David Suzuki Foundation to work with "government, business and individuals to conserve our environment by providing science-based education, advocacy and policy work for the social change that today's situation demands." His written work includes more than 54 books.

Stephen Lewis

Chair of the Board,
Stephen Lewis Foundation

Stephen Lewis is a respected activist, humanitarian, and tireless advocate for the rights of women. He is a Distinguished Visiting Professor at Ryerson University. He is an immediate past member of the Board of Directors of the Clinton Health Access Initiative, and Emeritus Board Member of the International AIDS Vaccine Initiative. He served as a Commissioner on the Global Commission on HIV and the Law. His work with the United Nations spanned more than two decades: he was the UN Secretary-General's Special Envoy for HIV and AIDS in Africa from June 2001-2006; from 1995 to 1999 he was Deputy Executive Director of UNICEF; and from 1984 through 1988 he was Canada's Ambassador to the UN. From 1970-1978, Mr. Lewis was leader of the Ontario NDP, during which time he became leader of the Official Opposition. In 2003, he was appointed a Companion of the Order of Canada. He holds 39 honorary degrees.

d'bi.young anitafrika

Performer

d'bi is an internationally celebrated Afrikan-Jamaican- Canadian dubpoet, monodramatist and educator. She is the published author of two collections of poetry, eight plays, two dubpoetry albums, and the sankofa trilogy. d'bi is the recipient of two Dora Mavor Moore Awards, the K.M. Hunter Theatre Award, Toronto Mayor's Arts Council Award and the Canadian Poet of Honour Award. She is the Artistic Director of YEMOYA International Artist Residency and the originator of the personal development methodology called Sorplusi. d'bi is also the Manager of the Arts, Activism and AIDS Academy—a recent project of the Stephen Lewis Foundation.

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The Stephen Lewis Foundation is deeply appreciative of the generous donations and in-kind support from all the sponsors and partners that have made the Tribunal possible.

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A heartfelt thank you to the Tribunal judges and presenters, and most importantly, to the courageous African grandmothers, and the organizations who support them, for coming forward at the Tribunal.

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