

Community-based organizations in sub-Saharan Africa are working with powerful dedication and effectiveness to turn the tide of HIV and AIDS. Our unwavering purpose is to work with equal determination to see that they get the support they need!

Spotlight on Grassroots

SPRING 2018



Siyaphambili, South Africa; Photograph by Margaret Wright/sLF



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Unleashing the Power of the People: Supporting Community-Based Leadership to End HIV&AIDS

From our inception in 2003, the Stephen Lewis Foundation (SLF) has been asserting that if only a critical mass of community-based organizations (CBOs) could receive adequate funding, they would turn the tide of HIV&AIDS in Africa.

Canadians have responded overwhelmingly to this clarion call. From years of programme support we now have overwhelming, concrete evidence that CBOs are indeed achieving powerful and lasting change.

The road is still long. With approximately one million AIDS-related deaths worldwide each year, and over one million new HIV infections in sub-Saharan Africa alone,

there is still much to be done. But it is clear from the herculean efforts of grassroots groups and people struggling to reclaim life and overcome the ravages of AIDS with dignity and dogged determination that, with the proper support and solidarity, they will prevail.

The SLF has supported over 300 organizations and more than 1,600 initiatives in 15 countries in sub-Saharan Africa hardest hit by the AIDS pandemic. But this is not a success story that should be counted only in numbers. It's about reclaiming human life and hope for the future. These are the lives of the women at the heart of the AIDS response in Africa, the children orphaned by the virus—many of them now adolescents and young people becoming activists, the indomitable grandmother caregivers, LGBTQ community advocates, and all of the people courageously living with HIV&AIDS, working with tenacity and dignity.



Uganda; Photograph by Emmanuel Museruka

Supporting Community-Based Organizations to Build Resilience

The impetus for putting the Foundation into motion was a single, essential insight: the work of community-based organizations is the key to turning the tide of HIV&AIDS. At a time when Africa was reeling from one of the greatest health emergencies in human history, the global response was frustratingly, bewilderingly slow. Out of necessity, grassroots groups began to form as an immediate and urgent response to the crisis. These CBOs were most frequently born out of the resolve of small groups of individuals who, after witnessing the devastation of HIV&AIDS in their personal lives, began to work determinedly to save their communities. Over the years they have grown and evolved to become important and trusted local institutions, and leaders in the struggle to overcome AIDS.

Community-based organizations see the problem—very importantly, we believe—from the perspective of those who have been infected with and affected by HIV&AIDS. They are helping to deliver life-saving antiretroviral (ARV) medication and health care, but they are also doing so much more. The task that CBOs have set for themselves goes far beyond tackling the medical aspect of the pandemic. Their programming aims, ultimately, to restore hope, dignity and possibility to individuals and their communities, so that they can begin to move forward again with their lives.

Our community-based partners are creating pathways toward resilience. Their holistic programs of material, emotional and psychosocial support are helping people whose lives have been devastated by HIV&AIDS to cope with crisis, rebuild their strength and regain their ability to face the future with confidence. Children stay in school, HIV-positive people stay on treatment, family units function, and small but reliable incomes are produced. Ultimately, there are signs that people have recuperated to the extent that they have regained their self-determination and can take active control over

their own lives. Children graduate from school and start working, women become community leaders and groups engage with their governments to claim their rights.

We call this ‘the resilience effect’, and it’s the great untold success story of the grassroots response to the HIV&AIDS pandemic in Africa.

Grandmothers Against Poverty and AIDS (GAPA), in South Africa, runs a camp for children to support those with painful experiences of AIDS-related grief and loss. It is a place of healing and loving attention. One young boy went home to tell his family that they need not worry if he retreats in silence to his room, that he needs the space to cry and grieve. Playing with friends, reading and singing were all identified as ways of coping with feelings of hopelessness, hurt, anger and sadness.

From **dlalanathi** in South Africa: The resounding, repeated comment in the bereavement support groups, the play for communication groups and the family support groups is, “I have never spoken to anyone about this before.” People have shared their feelings of stigma, isolation and mistrust, of troubles with family and neighbours, and of conflicts in the community. Being able to feel safe, share with others both hopes and deep sadness, and not feel so alone, is very significant for them.

Kimara Peer Educators & Health Promoters Trust Fund (Kimara Peers) in Tanzania shares, as one of our group members said in a recent meeting, “We need to break the stigma and silence around living with HIV by sharing our stories and letting others know they are not alone. In case no one has told you, you are doing an amazing job in taking care of yourself as well as taking care of their children under your care. You are loved and you are worthy. And you are not alone. I know how unbelievably hard it is to reach out to your peers, but I promise you it is worth it. You are worth it, and we should never despair.”

Selecting Partners for Impact



Reach Out Mbuya Parish HIV/AIDS Initiative (ROM), Uganda; Photograph by Edward Echwalu

The SLF has learned an enormous amount from working with 300+ partners, supporting over 1,600 initiatives. Early on we realized that identifying the right partners was impossible without visiting them first. Some proposals that we receive are bureaucratically perfect, while others may simply be a couple of handwritten pages, but with very compelling content about the needs of the community. Visiting groups with less polished proposals often reveals an outstanding organization that is the heartbeat of its community, working with child-headed households where no one else is present, or reaching an entire community of grandmothers raising countless orphaned grandchildren. So we don't rely solely on what's on paper.

We have developed a healthy set of criteria that assist us in identifying organizations that are rooted in and accountable to their community. For instance, we look for organizations that have women and people living with HIV&AIDS on their boards and on their staff, and that have a gender-based focus to their programming. We have also learned from our partners that counselling and emotional support to deal with trauma in the family, the

community, and amongst those who do the work is an essential ingredient to the success of every project.

Ultimately, though, it's about more than a checklist of criteria. It's the demonstration of community care, conviction, expertise and accountability that's so compelling. These grassroots organizations are filled with people (often women living with HIV themselves) who took the initiative to do something because they just couldn't stand by while AIDS ripped through their communities. It's the powerful impact of compassion and care that exists when it's your own brothers and sisters, parents, aunties, uncles, and children who are at the epicentre of the AIDS crisis. Many left their nursing or government jobs, their salaries and pensions, and plunged into the work of providing services and succour to their struggling communities. All of them shared—and still share—passionate beliefs about what must change. One of our partners summed it up beautifully when she declared that their work ensured “no woman dies without community around her and no grandmother is left to struggle to raise orphaned children alone.”



Zanzibar Association of
People Living with HIV/
AIDS (ZAPHA+), Tanzania;
Photograph by Alexis
MacDonald /SLF

HOW WE WORK

The Stephen Lewis Foundation's philosophy has always been firmly rooted in the notion that the expertise needed to turn the tide of HIV&AIDS in Africa is found at the community level, and that it is grassroots organizations that are keeping communities together, and resurrecting peoples' hopes and resilience.

We are driven entirely by the demands of these exceptionally effective grassroots organizations at the frontlines of the AIDS pandemic. There are no assumptions of Western hegemony, or top-down funding—we know that the communities are the experts on what they need, and what will, ultimately, defeat the pandemic. Our support, therefore, is structured to be quick, accountable (but not bureaucratic), flexible, holistic and sustained over the long term so that the organizations can have the certainty they need to carry out their work and expand its reach. We work with a women's rights, anti-colonial ethos, grounded in human rights and solidarity.

PARTNERSHIPS: We actively seek partnerships with groups that are of, by and for their communities, and include women and people living with HIV&AIDS on their boards and staff.

HOLISTIC APPROACH: Our partners know that the multiple traumas inflicted by the pandemic must be addressed together to rebuild lives, including physical, social, economic and emotional well-being.

DUE DILIGENCE FROM THE OUTSET: Before we decide to support an initiative, we visit every partner to evaluate its capacity, the strength of its connection to the community, and its accountability systems. We keep our overhead as low as possible, and our focus on the grassroots—hence our decision not to have offices in Africa. Our team of experienced field representatives regularly visit our partners for on-site monitoring and evaluation.

COLLABORATION: We maintain close contact with our partners, via regular communication and field visits, to facilitate relationships of trust and openness.

FLEXIBILITY AND CONTINUITY: There is no end yet to the pandemic, and the context continues to change. We accompany our partners as their work grows and deepens, and as they respond to new and emerging challenges.

Power and Partnership



Community-based organizations are a stabilizing presence for community members who are profoundly affected by the crises created by HIV&AIDS.

They are often stretched thin and distressed by the work, and their staff often contends with AIDS-related challenges themselves. The SLF understands that these groups are at the epicentre of the most urgent and life-saving responses to HIV&AIDS, and they do so with only a fraction of the resources they need and deserve.

Because of this, the SLF puts a very strong emphasis on relationship-building. This is not about cultivating friendship. It's about how to set up a dynamic that allows us to learn what's actually happening in a real way—when things go wrong, when things go right, when something unexpected happens. It's about creating a way of working that facilitates trust and honesty. It's about developing a way of *really* working together rather than acting out a pantomime of partnership. You can't pretend that there is no power dynamic, because unavoidably there is. One 'partner' should not have the prerogative of defunding the other.

Since its inception, the SLF has worked hard to become more informed and responsive. In finding a way forward with grassroots groups, we've arrived at an effective and mutually accountable way of working together. It's a hybrid—a fusion of the donor/recipient relationship and that of a political ally—and it brings about life-changing results.

Tanzania Grandmothers Gathering, Tanzania;
Photograph by Skystudios Africa

Measuring Our Success: The SLF Impact-Assessment Framework

Community-based organizations are successfully improving the human condition for millions of people infected with and affected by HIV&AIDS. To understand the real impact of their work, it is essential to document both the quantitative (material changes and numbers) and qualitative (emotional well-being) transformations. As one of our partners has put it starkly, “To win the HIV war, we must also win the battle of the mind.”

We have worked with our partners to develop a way to document both the quantifiable results of their work and, critically, the emotional roadmap to resurrecting resilience in families and communities devastated by the AIDS pandemic. The challenge was how to measure what lies at the heart of rebuilding the fabric of life, without relegating this critical dimension of the work to heart-warming sidebar stories.

We’re breaking new ground. The reports from our community partners, using the Impact-Assessment Framework, show that it is possible to measure change in critical areas of life that seem to defy measurement—for instance, emotional well-being, community connections and whether or not people are able to recapture hope for the future and have a renewed sense of purpose and direction. This, in combination with documentation of the astonishing numbers of people staying on ARV treatment, children entering and staying in school, grandmother-led income-generating projects, numbers of women being counselled on sexual violence and HIV&AIDS, etc. produces powerful evidence and metrics of results that reflect a complete picture of the enormous success of community-based, holistic interventions.



Children with Future in Zambia (CwFiZ), Zambia;
Photograph by Alexis MacDonald/SLF



Phoebe Education Fund for AIDS Orphans and Vulnerable Children (PEFO), Uganda; Photograph by Alexis MacDonald/SLF

“There is irrefutable evidence from the grassroots to show that community-based groups provide the best and strongest response to the pandemic. Making a contribution to the Stephen Lewis Foundation isn’t responding to those who languish in poverty, disease and despair. Quite the opposite! It’s a contribution to those who are triumphing over poverty, disease and despair, and we ask only that the triumph endure.” STEPHEN LEWIS



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