

Together We Are Stronger

The Stephen Lewis Foundation 2017 Year in Review



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FRONT COVER: "Together We Are Stronger"
is the motto of Grandmothers Against Poverty
and AIDS, South Africa, a long-time partner
of the Stephen Lewis Foundation

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Midlands AIDS Service Organization (MASO), Zimbabwe

Letter from our **Executive Director and Co-Founder**

ADMIT, I AM tremendously passionate about the contents of this Annual Review! It documents the critical importance our community-based partners give to psychosocial care in overcoming the history of hardship visited upon people as a result of HIV&AIDS.

When the Stephen Lewis Foundation (SLF) set out to develop an Impact Assessment Framework (IAF), collaborating with our grassroots partners in sub-Saharan Africa, we wanted to ensure that we could document *all* of the dimensions of the profound impact of grassroots initiatives on the lives of people affected and infected by HIV&AIDS. We were acutely aware that traditional impact-measuring systems have privileged quantifiable results—numbers of children in school, numbers of grandmother-headed households being supported, numbers of people living with HIV accessing treatment, etc. My colleagues and I felt a profound frustration, however, knowing that our community-based partners were *doing so much more* than providing support that could be counted. Our partners bring hope to families and communities with new support structures and the resilience to move beyond the agony of grief for so many loved ones lost to AIDS.



We all know, intrinsically, that learning to cope with grief, reclaiming a sense of well-being and hope is the most profound, human and necessary goal in overcoming a crisis. But how do you measure well-being? How could we capture the world-altering and essential moment when a child traumatized by the loss of her parents feels safe and emotionally well enough to play again and have hopes for her future? How to document all the remarkable, sensitive work of community-based organizations to bring grandmothers out of their mourning to embrace the future, muster the energy to raise another generation of children, and feel renewed joy and a sense of triumph? These aren't 'nice' by-products of good programmes, *they are the whole point*.

Tracking psychological and emotional change is not an academic exercise—the traditional measurements of success focussed on numbers and outputs lead directly to funding. It is imperative, then, to work with our grassroots partners to develop ways to document the potent centrality of psychosocial care and emotional healing, and to reconceptualize what success looks like. The funding for the community-based work on HIV&AIDS that makes a real and powerful difference depends on it.

The fabric of lives unraveled by AIDS is slowly being stitched back together, with care and urgency. This report highlights the sophistication and beauty of that work—a breathtaking testament to the insight and dedication of all the staff, counsellors and community volunteers who work with such dedication to restore a sense of well-being and promise to their communities.

A handwritten signature in black ink that reads "Ilana Landsberg-Lewis".

ILANA LANDSBERG-LEWIS

Executive Director and Co-Founder, Stephen Lewis Foundation



Introduction

Healing the Heart and the Mind

HIV&AIDS is a devastating global health crisis, and the international community is mobilizing billions of dollars to deliver urgently needed medication and improve health system services. However, for the countries that have been hit the hardest (which are primarily located in sub-Saharan Africa), AIDS presents much more than just a series of medical challenges. The human impact has been too profound.

The HIV&AIDS responders who have the most intimate experience of people's lived realities, the community-based organizations (CBOs), understand that multi-dimensional, holistic approaches are also needed. The big global programmes may be focussed on getting antiretroviral (ARV) drugs into hospitals, but the African CBOs have set a broader goal for themselves: bringing individuals and communities back to their former strength.

One of the important gaps that community-based organizations are filling in the overall HIV&AIDS response is in the area of psychosocial support. They can see that for some of the most pressing problems—such as keeping

children on treatment, or preventing new infections among girls and young women—psychosocial interventions are absolutely essential. And they understand that further progress is being impeded all across the board by the emotional and psychological damage people have suffered because of the virus. A person can't successfully manage living with HIV&AIDS while in the midst of trauma. **Kiambu People Living with HIV/AIDS (KIPEWA)**, Kenya, shares their assessment of the current situation:

Since ARV medication was introduced in Kenya, efforts have been concentrated on improving access to these drugs. This has had a positive impact in terms of reducing the number of bedridden clients. Psychosocial support activities, however, have been given less attention, which, in our opinion, is contributing to the rise of HIV stigma again and a lot of treatment default. ARV coverage in Kiambu County is high and the drugs are readily available. There, however, exists a gap in adherence since clients have little psychosocial support from the mainstream systems. **KIPEWA**, Kenya, identified this gap and strategized on strengthening psychosocial support to ensure that clients are encouraged to adhere to medication, as well as receiving much needed support for the many emotional and psychological challenges they are facing. In our view, if we can win the battle of the mind, we can win the HIV war!

CBOs are running thousands of mutual support groups

What forms of psychosocial support are community-based organizations providing? There is, of course, the individual, one-on-one counselling that's being conducted by trained psychologists and psychotherapists. The Stephen Lewis Foundation is supporting a number of powerfully effective organizations that are able to offer this type of assistance. But there are also thousands of mutual support groups being run by the CBOs.

Most of our partners have multi-dimensional programmes (providing a wide range of services, from medical care, to income generation, to improving children's education, to combatting violence against women), and psychosocial support is woven into all of this work through the use of mutual support groups. These groups are the main source of psychological and emotional care for the clients of community-based organizations.

In this report, we explore the different types of mutual support groups the CBOs are running, the many diverse needs they are meeting, and how people's lives change once they become group members.

Mutual Support Groups and the Power of Community

There are six main types of support groups that our community-based partners operate consistently, across all of the 15 countries in sub-Saharan Africa in which the Foundation provides support. The first, of course, are mutual support groups for people living with HIV&AIDS. These groups help people to adjust to the realities and challenges of living with the virus, and develop a new orientation towards life that is focussed not on the personal angst that comes with being diagnosed as HIV-positive, but on a plan for moving forward: “positive living.”

There are also special mutual support groups for children, who very often have lost their parents to HIV&AIDS and are now HIV-positive themselves. Groups for adolescents (both HIV-positive and HIV-negative) have a major focus on dealing with the critical sexual and reproductive health issues that start emerging in their lives. Groups for girls and young women are especially concerned with empowering them with greater control over their sexual futures. Groups for HIV-positive young mothers help them to manage their

own health while protecting their newborns from infection. Groups for LGBTQ people help them deal with the double burden of discrimination based on their sexual orientation, and discrimination based on their HIV status. And there are many, many vibrant groups for the grandmothers. More than 14 million children have been orphaned by HIV&AIDS in sub-Saharan Africa, and in the great majority of cases it is their grandmothers who have stepped in to care for them. Their mutual support groups are making it possible for grandmothers and grandchildren to thrive, despite the daunting challenges life has placed before them.

It's the undeniable power of human connection and community that enables all of these groups to have such a profound impact on their members' lives. As **KIPEWA**, Kenya, explains:

Support groups bring together people facing similar issues. Members of a support group usually share their personal experiences, and offer one another emotional comfort and moral support. They also offer practical advice and tips to help cope. It can be very helpful just getting to talk with other people who are in the same situation—a problem shared is a problem half solved! Our clients who have been continuously involved with their support groups tell us that they:

- are feeling less lonely, isolated and judged
- are no longer so distressed, depressed, anxious or fatigued
- are better adjusted to their situation
- have a clearer understanding about what they're facing
- have better coping skills
- are starting to get a sense of their own power and control again

People Living with HIV&AIDS

Groups made up of people living with HIV&AIDS form the centrepiece of the community-based response to HIV&AIDS. Many organizations supported by the SLF run at least one “positive living” group, and many of our partner organizations have brought together hundreds and hundreds of people living with HIV for mutual support. For example: **Nyakonya Self Help Group (Nyakonya)**, Kenya, runs 30 support groups with an average of 20 members each; at the **Catholic Diocese of Moshi Rainbow Centre (CDM)**, Tanzania, positive living groups have 590 members; **Ekwendeni Hospital HIV/AIDS Program (EHAP)**, Malawi, has 500 women and 382 men registered in these support groups; **Nyaka AIDS Orphan Project (Nyaka)**, Uganda, has 908 members in their positive living groups; **KIPEWA**, Kenya, has 1,012 people registered in their positive living groups; and **Panzi Hospital (Panzi)**, Democratic Republic of Congo, runs 30 of these groups, with an average membership of between 50 to 100 people each.

Considering all the benefits they provide—and at a minimal cost—it's no wonder that these groups continue to multiply. As **KIPEWA**, Kenya, observes:

Group members are much more likely to access antiretroviral treatment

We've found that running support groups for people living with HIV&AIDS has a high impact on morbidity and their retention in care, and also has a really significant impact on mortality and their quality of life. HIV-positive people who are members of support groups are more likely to disclose their HIV status to their families and other people close to them, and this

helps greatly to prevent the spread of the virus. Group members are also much more likely to be accessing antiretroviral treatment (ART), adhering to ART, and experiencing success with their treatment. It's the support group members who are most likely to achieve an undetectable viral load.

As a general rule, these groups are open to anyone in the community who is HIV-positive. But our partners have also established some more targeted positive living groups. For example, men have exhibited more of a reluctance to join mutual support groups (their membership numbers are almost always significantly lower than women's in the mixed groups), and CBOs realized that men would need extra encouragement and a greater sense of security before they would open up to a group. Men-only groups have been created in which, one of our partners explains, "they are able to share about their own 'male agendas' without feeling intimidated by their female counterparts." The groups also educate men about issues that are particularly relevant for them, such as domestic violence, and mobilize their members to do community outreach. For example, members of the men's groups facilitated by the **Rights Institute for Social Empowerment (RISE)**, Malawi, make door-to-door visits to educate other men, and are also raising awareness by hosting dances, football matches, and other games.

There are also specialized groups for women. For example, widows and sex workers are facing particular challenges that require focussed attention. In some communities, especially in Tanzania, Kenya and Uganda, there's a traditional cultural expectation that a widow will be "inherited" into marriage with another male family member after the death of her husband. Such forced marriages are a profound violation of these women's rights, and they also play a significant role in hastening the spread of the HIV virus. The widows' mutual support groups run by **Pendeza Africa (PENAF)**, Kenya, are focussed on empowering women to be able to have a choice about whether they will remarry. They also learn about their legal rights relating to marriage and inheriting their deceased husbands' property. Dedicated support groups for women who are engaged in sex work play an important role because of the high levels of stigma they often face in their communities, as well as the chronic violence and abuse to which their work exposes them. These groups provide a safe, non-judgmental space for the women to share their issues, and learn more about how to protect their health and their rights. As **Positive Life Kenya (PLK)**, Kenya, notes, "No one is forced to change her way of life, but anyone who wants to pursue a different way of life is supported to do so."

Children and Adolescents

Children and adolescents have unique needs. For the younger ones, the trauma of losing their parents to HIV&AIDS is still fresh and overwhelming, and, being children, their ability to comprehend and manage their HIV status themselves is limited. Teenagers are in a better position to begin learning how to live positively, or how to avoid infection with the virus, but they are confronting all sorts of new, unfamiliar difficulties—especially huge pressure to fit in with their peer groups, and confusion and uncertainty about how to navigate the terrain of sexuality.

The **Reach Out Mbuya Parish HIV/AIDS Initiative (ROM)**, Uganda, explains how they structure their mutual support groups differently for each age cohort:

UNDER 5 YEARS: children in this group do not know their HIV status because they are too young to understand or comprehend it. We deal mainly with their parents to address their adherence to medication, and we discuss the issues affecting the children in detail with their caregivers.

5–10 YEARS: most of the children in this group have not had their HIV status disclosed to them yet. The focus is on play therapy with toys, worksheets for drawing and colouring, and puzzles. Emotional issues and issues with their treatment are identified through the therapy and then handled by our counsellors or nurses, or referred for external support.

10–14 YEARS: most of the children in this age bracket are aware of their HIV status and are learning to cope with the situation. They are old enough to actively participate in learning sessions about positive living. When problems are identified, our adolescent peer counsellors talk to them, and make follow-up home visits to support them emotionally and psychologically. We also have a child counsellor on staff who counsels them on an individual basis.

15–24 YEARS: these young people all know their status, and the great majority of them have been HIV-positive since birth. Much of the discussion in these groups is focussed on the new challenges they are now facing related to their sexual and reproductive health, and group members are empowered to make good decisions and adopt healthy lifestyles. ROM also identifies individuals in these groups who are respected by the other youth and have a good reputation in the community, and provides them with training so that they can become adolescent peer counsellors.

The children who have been orphaned by AIDS are burdened with enormous grief. Dedicated attention is needed to help them accept the loss of their parents and begin to heal emotionally. **Sophiatown Community Psychological Services (SCPS)**, South Africa, describes the camp they ran last year for their therapy group for bereaved children:

ROM provides training so that they can become adolescent peer counsellors



Grandmothers Against Poverty and AIDS (GAPA), South Africa

As we know from past experience, many of the children were never properly informed about what happened to their loved ones, or were given pieces of misinformation which they struggle to make sense of. They needed to be given the space to understand and come to terms with the finality of death—a process which culminated in the camp when the children were supported through very painful experiences of grief and loss. For many it was also a safe space in which they could talk about their feelings, as well as about their current living conditions and care arrangements. The sense of loss extends well beyond the grief for the deceased loved one, as the children explained:

- I wish my father was still alive. I wish he could see all the bad things that are happening to me. I wish I could see him.
- No one can take the space of my mother in my heart. I get hurt when I see other children with their parents.
- I speak to my grandmother about my father and she tells me not to think about the things that have passed.
- We used to stay with both parents and my brother. Now we are living in a crowded space, with 8 other people.
- A lot of things changed after my mother died. I can't talk to anyone about it because I am scared.

Perhaps the most important outcome of the camp is that the children have learned that it is okay to express their feelings and that this in itself contributes towards the healing. One young boy went home to tell his family that they need not worry if he retreats into silence in his room, that he needs the space to cry and grieve. The children also explored coping mechanisms, which were particularly important for those who did not have much support in their home environment. Playing with friends, watching television, reading, sleeping and singing were all identified as ways of coping with feelings of hopelessness, hurt, anger and sadness.

Learning about Sexuality

This is an important focus area for the teenagers' mutual support groups because of the danger of HIV transmission through unprotected sex, and also because the stakes are so high in many other ways. Adolescent girls can pay a very heavy price for making one bad decision about their sexual lives. Along with HIV infection, there is the danger of pregnancy, expulsion from school, early marriage, entry into transactional sex work... the list goes on, and guidance and support are essential for protecting their futures. Of course, it isn't simply a question of engaging with the girls. One of the fundamental problems is a widespread lack of knowledge, on the part of both the boys and girls, about their sexual and reproductive health. Mutual support groups for adolescents are zeroing in on this issue.

We hold sessions where young people can have in-depth discussions with healthcare workers. The topics that are addressed include how the reproductive system works, how someone can get HIV, how to prevent pregnancy, the effects of teenage pregnancy, signs and symptoms of sexually transmitted diseases, how to avoid contracting sexually transmitted diseases, and how to deal with the peer pressure that affects the behaviour

of so many of the youth. When we hold these sessions we open them up to all of the young people in the Rumphi area, regardless of their HIV status. **National Association for People Living with HIV and AIDS, Malawi**

We're conducting group sessions for sexually active orphans and vulnerable children. Fifteen sessions were facilitated for youth aged 14–18 years. This has been a success, and the caregivers have noticed changes in their children after attending these sessions. We replicated the same workshops for the caregivers so that they were able to provide the neces-

sary follow-up support and education for their children. Caregivers are often afraid and shy to speak openly with their grandchildren about sex. The session provided a platform for them to share their anxiety about sexual issues and to get the necessary support. **Umtha Welanga (UW), South Africa**

Helping boys
and girls envisage
good, healthy
relationships



Zanzibar Association of People Living with HIV/AIDS (ZAPHA+), Tanzania

Social norms that condone the sexual coercion of girls and young women, and trivialize assault and rape, pose another major challenge. Mutual support groups for adolescents are the perfect place to address this issue, as youth are just in the process of forming their understanding of their own sexuality. The adolescents' mutual support groups devote a lot of discussion time to helping both boys and girls envision what good, healthy relationships can look like. In some cases our community-based partners are also setting up dedicated support groups to tackle the problem.

We are working with male and female students in “Students Against Rape” clubs in five secondary schools in Maun that admit children aged 13–18 years for post-primary education. WAR is able to raise awareness about gender-based violence issues in these clubs through debates, panel discussions and writing competitions. We take a holistic approach, discussing gender-based violence along with other sexual and reproductive health issues. The clubs also integrate skills development activities to help students develop their leadership abilities and confidence to share positive life skills with their peers. **Women Against Rape (WAR), Botswana**

Nyaka Primary School facilitates a support group for our primary school girls in grades 5 to 7 that focuses on healthy relationship building, assertiveness, reproductive health issues, and defensive techniques to combat abuse. There are 48 girls in the Nyaka Primary School group, and also Kutamba Primary School runs a similar group for 78 girls. The girls' groups meet regularly to talk about the challenges they face and try to seek solutions together with senior women teachers, who facilitate the discussions. **Nyaka, Uganda**

Young Mothers and Infants

Women who are diagnosed with HIV while they're pregnant are thrown into enormous psychological turmoil. In a moment, joy and anticipation are replaced with confusion, fear and dread. It is incredibly important to find a way to help these women quickly come to terms with their own status, learn to care for their own health, and begin taking the treatment that will make it possible for their infants to be born HIV-negative. When a young mother becomes overwhelmed and gives up hope, both her own life and the life of her newborn child are imperilled.

Community-based organizations are running special mutual support groups for this purpose. In addition to giving the women guidance, counselling and support to ensure that they can adhere to their ARV treatment, they also address the broader range of concerns that will have an impact on their ability to successfully mother healthy children. **Stepping Stones International (SSI)**, Botswana, explains the scope of their groups:

Their objective is to offer guidance to the young mothers on various issues such as self-care, seeking psychological support, how to bond with their babies, how to care for the infants' needs, and the prevention of pregnancy. In addition, the young mothers are engaged in activities that help them re-channel their anger and frustration away from their children and look towards positive goals.

LGBTQ Communities

Over the past decade, the situation of LGBTQ communities living with HIV&AIDS in sub-Saharan Africa has become increasingly dire. Bias and discrimination have been enflamed, stimulated in large measure by intensive evangelical efforts by right-wing churches in North America, and many countries have adopted new, extremely punitive criminal laws targeting the LGBTQ community. So many lives have been endangered, and public exposure as LGBTQ can bring a serious risk of imprisonment, violent assault, loss of employment and ostracism from the community. The fear this engenders is having a very negative effect on community members' willingness to come forward for testing and treatment, and their ability to maintain the positive outlook that is so critically needed for successful adherence. As a result, infection rates for LGBTQ communities in the region continue to rise. It can also be quite dangerous to form an organization for the purpose of reaching out to the LGBTQ community, as the organization itself may be subject to criminal prosecution.

Some very brave LGBTQ activists are willing to commit themselves to this effort, and the SLF is currently partnering with 16 of their small grassroots groups. Mutual support once more plays a key role in the work. One of our partners in Uganda explains what their programme is providing to members of the LGBTQ community living with HIV:



Blue Roof Clinic—Keep A Child Alive (KCA), South Africa

We offer a safe space at our organization where our clients can come and freely associate. Joining with others gives them a feeling of belonging in the face of double stigma, first for being LGBT and then for being HIV-positive. In addition, we make a counsellor available who helps our members living with or affected by HIV to cope, and builds their self-esteem to be able to live positively. We also arrange for referrals and linkages, especially for the clients who live in rural areas, so they can access treatment.

While many of these groups are newly established, we are already receiving reports of their successes:

One of the group members is a trans man who has now embraced his status and is living positively with HIV. His testimony to us is that since he has joined the programme his self-esteem has lifted, because the programme has made him realize that not all hope is lost, and there are people who still love and genuinely care about him regardless of his status. He now feels free to ask for advice from our nursing officer, who also gives him other medical service care from the organization's clinic whenever the need arises. This beneficiary has also encouraged his partner to start attending the various sessions we conduct on HIV&AIDS and other related issues, and they are both living a happy, positive life.



Pastoral Activities and Services for People with AIDS Dar es Salaam Archdiocese (PASADA), Tanzania

Grandmothers

One of the biggest unmet needs in the HIV&AIDS response is for support to the grandmothers, who are facing a truly daunting challenge in caring for the many millions of children who have been orphaned by AIDS in sub-Saharan Africa. The grandmothers, ranging from their early forties to their late eighties, are caring for multiple orphaned children—in some cases up to 6, 8 or even more than 10 children—with very limited financial means and serious health problems of their own. And the grandchildren, of course, must have intensive, special care, as they are grieving for the loss of their parents and are sometimes infected with the virus themselves.

Government assistance is minimal (very few countries are providing pensions or child-care grants), and most of the major global funders remain serenely oblivious to the African grandmothers' plight. Community-based organizations, however, have clearly seen these women's pressing need, and understand the critical importance of making sure that their efforts to raise the next generation are successful. More than 70 of our partners are running programmes for the grandmothers. Mutual support groups are absolutely central to these programmes, and their memberships are becoming quite large. For example, **Nyaka**, Uganda, has brought together over 7,000 grandmothers, and there are now more than 1,000 members in **KIPEWA's** groups in Kenya.

Because of the many burdens grandmothers have to shoulder, their groups usually tackle a range of different issues at once. As **Action for Rural Women's Empowerment (ARUWE)**, Uganda, explains:

The grandmothers groups conduct activities such as savings mobilization, joint vegetable gardening, collective marketing, home visits to care for the sick and bereaved, trainings in agriculture, savings and credit management, and group discussions about how to care for the medical and emotional needs of their children.

In fact, it's common for grandmothers groups formed for a single purpose to naturally expand their focus over time.

Our village savings and loans groups were initially formed to allow grandmothers to save a little money and run some small businesses, but they have turned out to be very effective support groups. They were organized after a series of income generation trainings, and the groups have grown—there are now 33 groups bringing grandmothers together in their neighbourhoods (990 grannies in total). They have become support groups for sick members and for any social activity, and during the meetings the grandmothers are able to discuss their psychological challenges. They dialogue and share new ideas among themselves, which helps restore their emotional balance and strengthens their resilience against stress factors. The social cohesion for self-help goes far beyond the groups' initial purpose. **ROM, Uganda**

Income Generation

The psychological and emotional benefits of reconnecting with other people, and realizing that you are not alone in your struggle, are great for people who have been infected and affected by HIV&AIDS. There are many mutual support groups, as detailed above, that are designed with this psychosocial impact as their primary goal. But the power of community

works its magic whenever grassroots organizations bring people together for a shared purpose. Income generation groups are actually producing some of the most significant improvements in people's psychological well-being. Despite being focussed on very concrete, material concerns, their therapeutic value is quite considerable.

The most immediate reason for their success is that they help lift the additional burden that poverty places on the psyche of a person living with HIV&AIDS. As **Nyimbwa Multi-Purpose Organization of People Living with HIV/AIDS (NYIMUPHA)**, Uganda, explains:

Many people living with HIV become emotionally detached, stressed and desperate, especially when they don't have money or the means of survival. They feel that the world is caving in on them because of their HIV-positive status. They go through further self-stigma and hopelessness. With income-generating activities one is made busy working with others,

Lifting the extra
burden poverty
places on
one's psyche

and this reduces the time alone spent on sadness and self-criticism. By the end of the day one has some money for transport and family/personal welfare, and this ability to take care of yourself puts a person's mind at rest and peace.

The “coming together” effect operates so potently in income-generating groups that our partners have integrated it very consciously into their programming strategies. As **Grandmothers Against Poverty and AIDS (GAPA)**, South Africa, explains:

Our approach to emotional and psychological support is activity-based. With the grandmothers we use activities as a means of processing emotions as well as a means to achieving an “end,” an end product when the day is done. This is what happens with our income-generating project in which grandmothers are taught to make arts and crafts with beads. As our motto “together we are stronger” suggests, we believe in collective effort, hence our emotional and psychological support is based on collective activity, which facilitates sharing and processing emotions, and healing well together.

The Groups Grow and Evolve

When they set up a new mutual support group, community-based organizations typically have a big role to play in managing the group's affairs and keeping them running. Our partners initially provide office space for group meetings, bring members into the group, set the agenda and facilitate discussions, provide the relevant trainings (as well as material inputs, especially for the income generation groups), and monitor the group's progress, troubleshooting problems. The CBO is definitely in the lead at the start, while at the same

time consciously supporting the group's growth—as **Community-Based Care Foundation (CBCF)**, Zambia, explains, “We are advising them wherever we can, but encouraging them that they are masters of their own destiny.”

Over time, quite consistently, the group members' own skills and leadership abilities begin to flourish, and the groups become much more self-reliant and self-directed. For example, **Ripples International (Ripples)**, Kenya, reports seeing many signs of growth:

Our groups can now write their own records (such as minutes and monthly savings records). They meet under the leadership of their own chairpersons and secretaries, and can convene meetings, set agendas and discuss them without assistance from our staff. They've been successful in devising income-generation initiatives that have borne fruit, such as the Nthimbiri group, which is now running a grass farm.”

And **EHAP**, Malawi, reports:

“All of our support groups now carry out their activities independently. For example, they conduct group therapy meetings on their own, and they plan and implement their activities

“We're encouraging them to see that they're masters of their own destiny”



Phoebe Education Fund for AIDS Orphans & Vulnerable Children (PEFO), Uganda

on their own. These activities include advocating for HIV testing, encouraging people to adhere to their ARV treatment, and educating people to stop stigma and discrimination against those who are infected with HIV.”

The trajectory that our community-based partners report to us again and again is a path from dependence to autonomy, which most often ends with the mutual support groups registering with their governments as free-standing entities. For example, as **NYIMUPHA**, Uganda, reports:

One of our group has been supported to register a group of people living with HIV in Kisooba village. It has a membership of 20 people, 5 males and 15 females, and of these 11 are youth. Its focus is to live a happier, healthy life. They run an internal savings and loan scheme and a piggery project. The group was registered at the sub-county level and district level under number CD-503 this August.

With official registration the mutual support groups become eligible to participate in various government programmes, and often to receive some form of government funding or assistance. **St. Francis Health Care Services (St. Francis)**, Uganda, reports that:

The Source of the Nile grandmothers support group is a registered group that is currently linked to the surrounding government programmes like Operation Wealth Creation, and so can benefit from the privileges that the government avails to all registered groups in the country. The grandmothers recently received a Friesian cow from this programme.

A good number of the groups have gone even further, evolving into small grassroots organizations that are now providing assistance to their communities independently. For example, the **Maasai Women Development Organization (MWEDO)**, Tanzania, reports that over the past year, 52 of their support groups were registered, and they started their own credit society. And **SSI**, Botswana, reports that their Maferisi grannies support group has registered a company and sourced government funds to enable them to build an old age home and a cultural centre to empower girls with life skills.



Tracking Psychological and Emotional Recovery

As KIPewa, Kenya, observed, half the challenge when working with people who are infected and affected by HIV&AIDS is “winning the battle of the mind.” But how do you know that you’re winning?

Many of the remarkable improvements that our community-based partners are bringing about in their beneficiaries’ lives are easy to track, such as more and more people being diagnosed and entering into treatment, children returning to school, or impoverished families starting to earn enough income to meet their basic needs. These stories can be told with numbers. Overcoming despair, finding hope once more, and feeling able to tap into your inner strength to confront life’s ongoing challenges, however, are much more intangible—even though no real progress can be made in their absence.

For the past several years, the SLF has been working with our partners to try to devise a way to document and systematically track psychological and emotional change. The solution we’ve arrived at together is to begin recording the external signs of psychological growth. While no one can look directly



Swaziland Positive Living (SWAPOL), Swaziland

into another person's mind or heart, it is possible to observe inner transformations through behavioural change—by looking at what the CBOs' beneficiaries are now saying and doing.

There are 14 major signs of psychological and emotional growth that our community-based partners have identified, and have begun documenting in the progress reports they submit to the SLF. They're finding that their clients are consistently:

- 1 Expressing themselves more freely
- 2 Sharing their stories and experiences
- 3 Actively participating in group processes
- 4 Thinking more positively
- 5 Less withdrawn, ready to smile and laugh
- 6 Making safer and healthier choices
- 7 Making contributions and helping others
- 8 Communicating better within their families
- 9 Developing new skills
- 10 Embracing challenges, not hiding from them
- 11 Starting to dream and plan again
- 12 Opening up to new people and relationships
- 13 Relying less on the CBO for support
- 14 Taking on leadership roles, big and small

We're sharing some highlights from our partners' 2017 reports on this subject. Sign by sign—with each step—you can see people's resilience returning. Trauma is becoming more manageable, and new hope and enthusiasm for life are emerging.

1 Expressing themselves more freely

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. **dlalanathi, South Africa**

The teachers at Vezokuhle school are saying that they are seeing progress in the children who have attended our children’s groups, and the children themselves have said they learnt a lot. The children shared with us that talking about death and talking about something that is hurting you is important. The teachers have noticed that the children now know what is right for them and how to express their feelings. This is especially observed when they are angry, as they have learned how they can express their feelings in a way that won’t hurt other people. **dlalanathi, South Africa**

Children who were not able to effectively express their feelings are now able to express themselves verbally, by saying “I am angry” or “I am sad,” rather than acting out, crying, shouting, hitting and so on. **Keep a Child Alive (KCA), South Africa**

The psychosocial group we run has impacted the grandmothers immensely. They are able to express their emotions freely, as they’ve found a safe space for each other to share in this group. The grandmothers are able to contribute and help others deal with their emotions through peer sharing, and catharsis emerges. The confidence boosts we are seeing in them come from the way the groups are fostering independence and emotional security. **GAPA, South Africa**

We’re now working with 250 grandmothers, and at least 70% of them are able to confidently air out their issues in front of others, as opposed to before the project. You can see their confidence in the authority of their speech and assertiveness, their standing posture, how audible they are now, and how free they are to say what they want. This is such a big achievement because the grandmothers come from a generation that didn’t support women speaking in public. **ARUWE, Uganda**

2 Sharing their stories and experiences

Young people are feeling relief from their stress when they share their stories and challenges with different people. Everyone has his or her story, with its ups and downs. Challenges are part of being human, and the strategies for handling them vary depending on the environment, and the opportunities and capacities one has. While listening, the children find that everyone shares a similar story, and they learn from others about how they passed through the same situation. They try to copy their peers. We’re seeing the children accepting the



Midlands AIDS Service Organization (MASO), Zimbabwe

challenges they face, even abuse or violence, finding the courage to speak about these challenges with their peers, and leaders and elderly people, and becoming stronger and empowered to overcome them. **Action for Community Development (ACODEV), Uganda**

As one of our group members said in a recent meeting (to big applause): “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.” **Kimara Peer Educators and Health Promoters Trust Fund (Kimara Peers), Tanzania**

3 Actively participating in group processes

We find that there is always an increasing number of children, adolescents and their families who are really engaged, both physically and emotionally, with the groups' activities.

Zanzibar Association of People Living with HIV/AIDS (ZAPHA+), Tanzania

The grannies are participating very actively in their groups, hence they are able to identify the challenges they need to tackle and figure out appropriate solutions together with the

FAST officers. Friends of AIDS Support Trust (FAST), Malawi

**Members take
turns being leaders
so everyone can
feel their potential**

Members of the micro-credit groups take turns being leaders of their groups. This helps every member feel the potential in them. Each group member feels trusted by the other members. Psychologically and emotionally they grow stronger in terms of personal dignity, and less frustrated or stressed by what has happened in their lives. **Kimara Peers, Tanzania**

When we first set up these support groups for children infected and affected by HIV&AIDS, our project officers would have to mobilize and facilitate, and make sure that the children would meet monthly as planned. Now a sizable number of children are showing leadership qualities, and have taken on the role of facilitating the sessions themselves. Of the 17 support groups, all of them are being facilitated by some of the children. They always look forward to the next support group meeting. The children have even created groups on social media platforms such as WhatsApp where they continually share experiences, discuss various issues and challenges they are facing, and remind each other of the next meeting date. **Chiedza Child Care Centre (CHIEDZA), Zimbabwe**

We're seeing a continuous improvement in the members of our people living with HIV&AIDS groups, in terms of their participation in group processes, their group conflict resolution management, and their participation in community development programmes, such as cooperatives, women's clubs and other social groupings. For example, the support group in the Lukangaba zone has been linked with and is participating in the area nutrition committee. **Luapula Foundation, Zambia**

4 Thinking more positively

This is so important, especially for the children who lose their guardians, who they saw as their only hope for survival. Losing a close relative is a tragedy for most people and it affects a person's psychology in a way that is common to every human being. When an orphan loses someone who was willing to take care of them, and take them on with all of their vulnerabilities, of being HIV-positive and also having the needs of a child—it is important for such children to be able to accept that death has happened, but life can



Women's Legal Resources Centre (WOLREC), Malawi

still continue in whatever state it will take. If a child can rethink positively in that manner, then she or he will not be so badly affected, and can plan in a strategic direction with higher hopes for the future. **ACODEV, Uganda**

Because of their membership in the support group, and its stigma sensitization activities, some of the people living with HIV&AIDS who had been suicidal are now making better choices in their lives, and are able to encourage others who have the same HIV status. For example, one of the members of the Mano support group attempted to kill himself by swallowing acid. He was hospitalized and has recovered, and he has now accepted his status and is encouraging others to make better decisions. **Luapula, Zambia**

At the inception of these support groups for children infected and affected by HIV&AIDS, most children expressed a lot of uncertainty about their lives, doubting if they would live to see the following year, or have a normal, happy life, or ever marry and have a family because of their HIV status. Through the support groups, many of these children have started believing in themselves, and some are envisioning running flourishing businesses or occupying big leadership posts in companies, as well as having their own families.

CHIEDZA, Zimbabwe

A member of one of our young caretakers groups shared with us, “I’ve learned that losing your loved one doesn’t mean you’ve lost everything. It shows that you are living, and it’s a test of courage. You have to cry and let it go and move on with your life.” **Ekupholeni Mental Health and Trauma Centre (Ekupholeni), South Africa**

The grandmothers are more optimistic and have changed their fears into hope that their grandchildren will be able to grow up to realize their full potential in life. **Women Fighting AIDS in Kenya (WOFAK), Kenya**

5 Less withdrawn, ready to smile and laugh

Being involved in so many discussions and trainings has a special result on people. They’ve learned that worrying will never put food on the table, but smiling just may, and that no one wants to go near someone with a long face. Our staff make sure to wear a warm face always, and the energy is transferable. A family kind of setting is encouraged and when the clients see it they learn it and they are happier. People often joke, especially the grannies, that they cannot come into the “big office” in tattered clothes. “You must be smart, because you don’t know who you might meet!” **KIPEWA, Kenya**

6 Making safer and healthier choices

One of the members of our young caretakers groups shared with us, “The way I used to behave was because I was looking for ways to reduce my stress. But when I talked and took out what was inside of me and shared it with other group members, I found real stress release. This is what has made my life begin to change. I’m now planning for my next move.” **Ekupholeni, South Africa**

Convincing people to take better care of themselves can be a challenge, especially for some of the single mothers who say they have to do all they can to feed their little ones. The brave ones have taken on full responsibility for their own health. They have changed their diet to accommodate healthy eating, and are even preparing food differently! Simple things like eating fruits and taking water frequently are being embraced. We find ladies these days

carrying water bottles in their hands. This was sometime back looked down upon as it was thought to be a habit for rich people, expensive and proud in nature. This thinking has changed. **KIPEWA, Kenya**

We find ladies
these days
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Most of the young girls are aware of the conditions and situations that can put them in danger of being infected by HIV and getting pregnant. They say “NO” to those strangers who offer them money or other kinds of gifts. We heard one grandmother saying, “You cannot find a girl and boy in secluded and dark areas, our girls are nowadays aware, they know what might happen.” **Okoa Maisha Ya Watoto (OMAWA), Tanzania**

Fewer girls are becoming pregnant, and more boys are making every effort to protect children and young girls, rather than doing anything harmful to them. **Keiskamma Trust (КТ), South Africa**

7 Making contributions and helping others

The members of our groups for people living with HIV&AIDS continue to advocate for HIV testing and are fighting against the stigma and discrimination associated with HIV&AIDS. They do this by holding awareness meetings in villages to communicate key messages about HIV. They’re also working as home-based care volunteers, visiting people in their homes and counselling them on nutrition and ARV treatment compliance. **EHAP, Malawi**

The People Living with HIV&AIDS (PLWHA) group members are now counselling and supporting each other in the group, and also reaching out to other community members. For instance, the group members are promoting behavioural change by providing counselling and outreach to the community. They’re supporting other group members with farming when they cannot cultivate on their own because of illness. Some are conducting home-based care visits, and providing emotional and psychological support by visiting chronically ill people. And they’re sharing the knowledge they’ve gained—for instance about soya bean production, chicken and livestock rearing, and village banking—with their families and members of the community. **Luapula, Zambia**

Many of the children have been noted showing acts of kindness, such as helping their peers out by giving them books and pens so that they can write down their lessons in class, or taking their grandmothers to the hospital when they are sick. **Phoebe Education Fund for AIDS Orphans and Vulnerable Children (PEFO), Uganda**

The grannies are now able to make donations to other vulnerable groups. For example they donated clothes to the flood victims, and they are also donating relish to three local schools since the government is only providing mealie meal. **Hope Tariro Trust (ННТ), Zimbabwe**



Chiedza Child Care Centre (CHIEDZA), Zimbabwe

8 Communicating better within their families

There is confidentiality and confidence within relationships; these homes now welcome visitors, friends and relatives, and the children are well taken care of. **Isis-Women's International Cross-Cultural Exchange (Isis-wicce)**, Uganda

As a result of the Man to Man groups, we are seeing a number of men starting to escort their wives to the health facilities, where they access antenatal care services together. **RISE**, Malawi

Introducing playful activities into the grandmothers group has made them aware of the importance of play for the children. As one grandmother remarked during an art activity: “I never understood why my grandson would be so glued to the book when he was drawing. I would shout at home and threaten to tear the book away from him. I never knew how nice it is to draw. From today I will let him draw for however long he wants, because once one starts it is not easy to stop.” **SCPS, South Africa**

9 Developing new skills

With the introduction of our new mobile library, pupils from the partner schools have come to love group reading sessions, through which they have greatly improved their communication and social skills. The children have gained the ability to understand others and express themselves clearly using words and expressions. **PEFO, Uganda**

Most of our beneficiaries are more hopeful and looking at life more positively, and so are now accepting the idea of learning new skills, especially vocational training, crop growing and animal management. The younger beneficiaries are happier, and they are developing their interpersonal skills and relating better with their friends. **Kyetume Community-Based Health Care Programme (КСВНСП), Uganda**

Some of the children join the kids’ clubs full of unresolved issues, like no one ever telling them their parents are dead or that they are living with HIV. At the start they would not know how to deal with their anger and would cry and fight a lot over small disagreements with their peers. With time they learn about “managing anger,” and how to talk about “the saddest things in their lives” and “who is still there for them.” They develop new emotional coping skills over time within the groups. **Kimara Peers, Tanzania**

10 Embracing challenges, not hiding from them

Our PLWHA support groups managed to organize themselves to participate in the Agricultural Block Show, where they displayed the products they are producing such as energy and protein supplements, soya milk, soya coffee and soya munkoyo (a local drink). They won the first and second prizes for southern and northern district regions respectively, and they took second position in the food-processing initiatives competition. **Luapula, Zambia**

The clients we’re providing psychosocial support to because of gender-based violence are less fearful and anxious, and they’re better able to make independent decisions about their lives. They are taking charge in decision-making to ensure their own safety and well-being, for example by laying criminal charges against abusive husbands or intimate partners. **Swaziland Action Group Against Abuse (SWAGAA), Swaziland**



Catholic AIDS Action (CAA), Namibia

Even though a situation may seem hopeless, these grandmothers have developed the inner strength to press on. They are much more able to deal with tough situations as compared with before. For instance, when drastic weather changes started negatively affecting their crop produce, the grandmothers were able to rely on group support, group savings to purchase some food stuffs, and their revolving loan scheme to get capital for farm inputs. In addition, because of the trainings on good postharvest handling, most of them were able to preserve their seeds for replanting, especially vegetables and beans. **ARUWE, Uganda**

11 Starting to dream and plan again

Members of our groups are role modelling and helping others to be focussed on a good, prosperous future even though they are living with HIV. Exercises like “dreaming and back lighting” help people to view their lives five to ten years ahead as if they are already there. Then they think back about how they would have managed to become so successful, and who and what would have been helping them to make it work so well.

Kimara Peers, Tanzania

One of our grandmothers told us “I now dream of repairing my old house, which was not the case before. With the savings from my crop sales I have bought iron sheets so far.”

ARUWE, Uganda

Our clients have shown a tremendous improvement in their attitude towards life. They have more zeal and a desire to live out even their dreams that had long ago died and been buried. **Swaziland Nurses Association Wellness Centre for Health Workers and their Families (SNA), Swaziland**

12 Opening up to new people and relationships

The orphaned children are making relationships with different people, for example community councillors, church leaders, community members, elders in the community, school heads, teachers, politicians and health workers. Opportunities come from every corner, even if not in the form of hard cash. Their sympathizers become many, and these are the people they can run to for different types of advice when they meet new challenges in life. They get positive solutions to their problems, which relieves their stress, and they begin thinking in the way of the people who have given them advice. Life continues. **ACODEV, Uganda**

13 Relying less on the CBO for support

The members of our Young Generation Alive groups are continuously developing new mechanisms to raise funds for their projects, like the higher education project. Individuals within the group have started their own income generation activities, like making chapatis to raise the transport fare to and from university for one of the youth who is pursuing a diploma in civil engineering. **Makerere University–Johns Hopkins University Research Collaboration (MU-JHU), Uganda**

14 Taking on leadership roles, big and small

Our groups are now discovering that they can autonomously resolve some child abuse cases without referring them to us, and are using the group approach to follow up on the cases that would be difficult to handle on a personal basis. **KCBHCP, Uganda**

The groups have taken it upon themselves that there will be no more early marriage in their communities. If a household is found wanting, group members report it to the village headmen who further report it to CBCF staff and other stakeholders, to arrange for the victim support unit to intervene. **CBCF, Zambia**

Members of our mutual support groups are becoming involved in the village-level political committees, and some of the support group members have taken on roles as counsellors at the local clinic. **Malealea Development Trust (MDT), Lesotho**

The grannies' tea group is now an established group that is known in the community, and their leaders are involved in various community development events. They were part of the team that carried out the asset mapping for our programme, and they have identified gender-based violence hotspots and came up with solutions for the problem. **SSI, Botswana**

Our groups have decided that there will be no more early marriage

The Glory Disability group members are highly respected in the community. They have been called upon and also visited by local leaders, and involved in conflict resolution at the local level. This has given the support group members confidence to engage in activities to improve the well-being of their communities. **LVCT Health (LVCT), Kenya**

Five of our grandmothers have even become involved in local council meetings, where they don't sit as observers but are active participants. They are able to engage with the council leaders to provide better services. One grandmother, 51-year-old Namuli from Gayaza S/C, who is caring for 6 children, was able to convince her local council and chairpersons to get justice and redress for the violation of her property and land rights. After the leaders intervened, she was able to secure her 2 acres from being grabbed by an unfair landlord. **ARUWE, Uganda**

One of the group leaders, Agatha James Nindi, is now contesting for a leadership position in her local government authority. **Kimara Peers, Tanzania**

So many people have expressed the sentiment that HIV&AIDS has brought them down to the lowest point of their lives. With the support of these CBOs, all of those living with HIV&AIDS—including the children, the teenagers, men and women, the widows, the sex workers, young mothers of infants, LGBTQ communities and the grandmothers—are finding new strength within themselves. They're reclaiming their enthusiasm for life and their hopes for the future, and they're becoming a positive force to be reckoned with.

Financial Overview

Programmes

We are deeply committed to delivering the majority of our revenue to the community-based organizations with which we work. Between 2003 and June 2017, the Stephen Lewis Foundation disbursed and committed a cumulative \$106.2 million to programme spending, including direct support to over 1,600 initiatives with 315 CBOs in 15 African countries. This amount represents more than 83% of total expenditures over the past 14 years. To read more about our work with African partners, please visit: stephenlewisfoundation.org/what-we-do

Administration

Administration is essential to the success of every charitable organization. At the Stephen Lewis Foundation these costs are associated with day-to-day operations and expenditures that ensure we are accountable for how funds are being allocated. We are committed to keeping these administrative costs as low as possible through in-kind donations and pro bono support. We are proud to report that, again this year, our administrative costs are just under 10% of our total revenue. For more information, please visit: stephenlewisfoundation.org/who-we-are/financials

Funds development

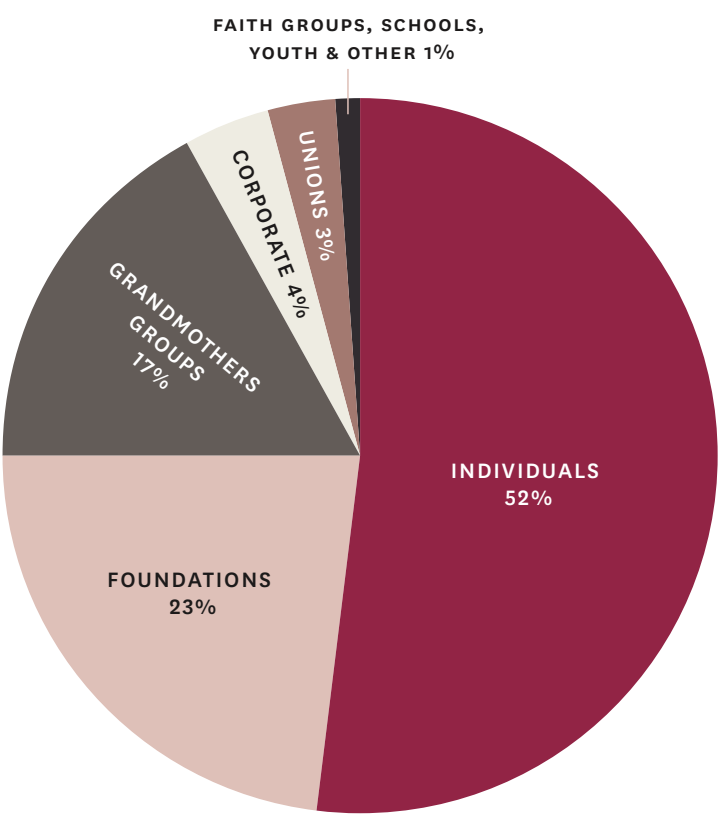
In order to continue to support the innovative programming developed by our African partners, the Stephen Lewis Foundation has increased its fundraising capacity to engage supporters through a variety of recognizable initiatives, such as special events that feature the voices and work of our partners, and by encouraging critical monthly donations. In 2017 we spent just under 9% of our revenue to support awareness-raising and fundraising, ensuring that over 80% of funds raised continued to go to programme work.

For a copy of the Foundation's full audited financial statements and the link to our annual Canada Revenue Agency (CRA) charity returns, please visit: stephenlewisfoundation.org/who-we-are/financials

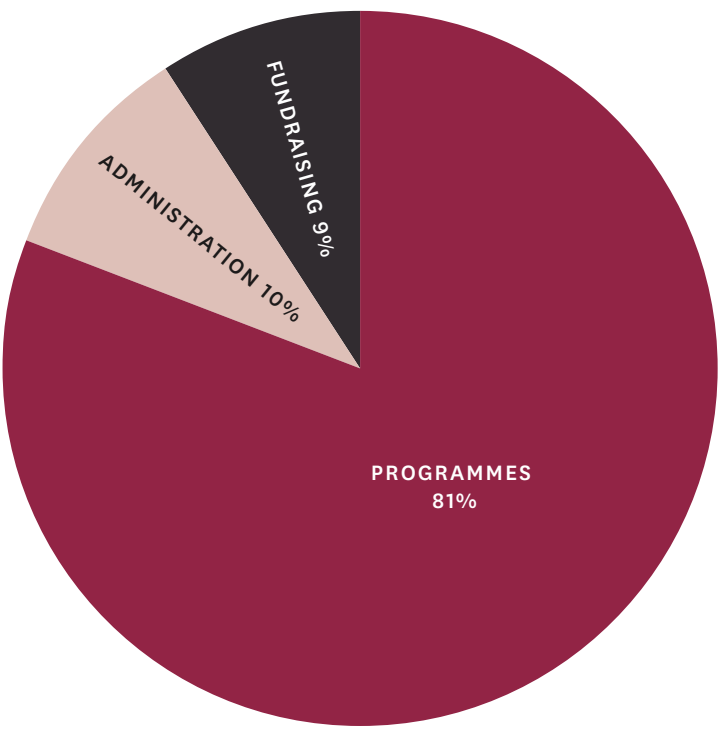
The Foundation's fiscal year runs from July 1 to June 30. Our auditors are Grant Thornton LLP Chartered Accountants. The Foundation's charitable number is 89635 4008 RR0001.

If you have questions about our financial statements, please call 1-888-203-9990 ext. 244 to speak to Esther Vise, Director of Finance.

Where our support comes from



Where your money goes



About the Stephen Lewis Foundation

SLF Partnerships

The Stephen Lewis Foundation works with community-based organizations (CBOs) that are turning the tide of HIV&AIDS in sub-Saharan Africa. Since 2003 we have funded over 1,600 initiatives, partnering with 315 community-based organizations in 15 countries. Most of these organizations were born of the resolve of small groups of individuals who, after witnessing the devastation of HIV&AIDS in their own lives, began to work determinedly to save their communities. Over the years these organizations have grown and evolved to become trusted and important local institutions, and leaders in the fight against HIV&AIDS.

The staff and volunteers of CBOs are unwavering in their commitment to help people access the health care they need, provide counselling and support, and restore hope in every home and community. They recognize that gender inequality is driving the AIDS pandemic in Africa, and that it is necessary to have specialized programmes to support women and girls. They know that the best way to secure decent futures for the millions of children orphaned by AIDS is to empower the grandmothers who are caring for them. They're reaching out to LGBTQ communities who are struggling to survive, not only with HIV, but also with intense discrimination and persecution.

Our community-based partners have set for themselves the ultimate goal of restoring the resilience of the people and communities who have been hardest hit by HIV&AIDS. Their holistic programmes, which combine medical and material assistance with emotional and psychosocial support, are life changing. They're enabling people who are infected with and affected by AIDS to cope with crisis, rebuild their strength and face the future with confidence.

The SLF has been working with our community-based partners to track the long-term impact of their work. With every *Year in Review*, we present the evidence that because of their dedicated, loving efforts, CBOs are contributing to profound changes in people's lives.

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To donate from the United States, please visit the Tides Foundation at <https://donatenow.networkforgood.org/tidesfoundation> and select “Grandmothers to Grandmothers” from the drop-down menu that prompts “I want my donation to be designated toward:”

To start or join a grandmothers group in Australia or the United Kingdom, you can contact our Grandmothers Team at campaign@stephenlewisfoundation.org