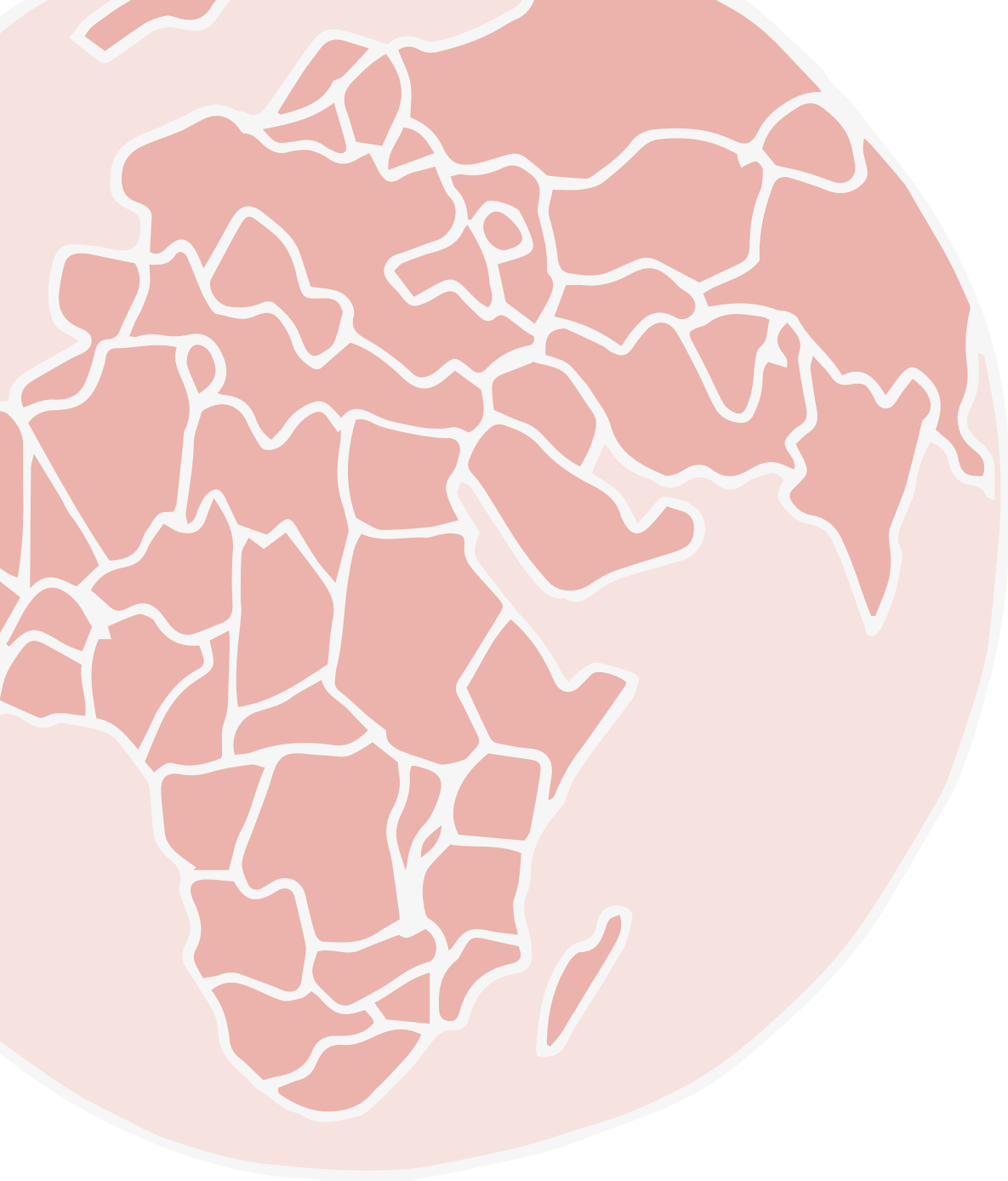


Healing, Health, and Hope

**A Case for Support for
Prioritizing Home-Based
Care and Community-Based
Responses to HIV and AIDS**



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EXECUTIVE SUMMARY

Home-based care (HBC) is a vital part of the response to the HIV and AIDS pandemic in sub-Saharan Africa. Since 2005, the **Stephen Lewis Foundation (SLF)** has supported grassroots, community-based organizations (CBOs) in their work to turn the tide of HIV and AIDS using HBC models as a primary care and support method. Today, the SLF partners with more than 125 organizations across 15 sub-Saharan African countries, many of which continue providing critical HBC to community members.

This case for support compiles and shares the collective experiences of 7 of the SLF's partners in undertaking HBC. It finds that, in addition to playing a critical role in the HIV and AIDS response, home-based care is central to the delivery of holistic health care more broadly. Home-based care is key to cultivating personal well-being and connection, combatting discrimination, increasing personal agency, and enhancing health equity and gender equality.

At a time when the ongoing COVID-19 pandemic is further exacerbating health inequalities and when international assistance for HIV and AIDS has been steadily decreasing, this report demonstrates the importance of continued and increased international (government, bilateral, philanthropic) funding for home-based care. Support for HBC contributes to international and national development priorities, including the **Sustainable Development Goals** (SDGs) and the Canadian **Feminist International Assistance Policy** (FIAP) and safeguards communities against future pandemics.

INTRODUCTION

WHAT IS HOME-BASED CARE?

Home-based care (HBC) was developed out of necessity as a response to the health needs of communities throughout sub-Saharan Africa. It reflects the idea that health services must reach people both where they are physically located and feel safe – their homes and local communities – and where they are emotionally, socially, and mentally. By delivering health care in a client's home, HBC workers eliminate transportation barriers, reduce the impact stigma can have on decreasing a person's willingness to access services, and increase the safety and comfort a client feels in opening up and sharing their struggles.

Home-based care includes a wide variety of primary health services for individuals at every stage of the life cycle, including, but not limited to, pre- and postpartum care, routine vaccinations, health education, management of common illnesses, and follow-up of discharged patients. Depending on the country and context, home-based care is delivered by health care professionals, such as midwives and nurses, or by trained volunteers. A number of different terms are used to refer to home-based care workers, including Village Health Team (VHT) Worker, Community Health Worker (CHW), or Community Health Extension Worker (CHEW).

Sub-Saharan Africa is home to 67% of all people living with HIV worldwide,¹ but has just 3% of the global health workforce. In fact, in 10 of the 15 countries where the

SLF works, there is only one doctor for every 10,000 people. In rural communities with limited traditional health care infrastructure and/or cost-prohibitive transportation, home-based care workers are able to reach marginalized and geographically isolated community members who would otherwise be missed by centralized health care systems. Where national health systems fail to reach people, community-based organizations (CBOs) are filling the gaps and consistently serving their communities.

Home-based care workers – overwhelmingly women, mostly volunteers, many HIV-positive themselves – visit countless homes each day, travelling great distances, most often on foot or by bicycle. They dispense drugs and food and provide peer-support and counselling. They bathe their

1. UNAIDS, **Fact Sheet – 2021**, p.2.



Swaziland Nurses Association, Eswatini, Photo by Claudia Ramos

clients and carry out household chores. They meet with children to ensure that their needs are being met, and identify families that are struggling and need more support. They provide palliative care for those in the last stages of AIDS. Above all, they provide a vital service by delivering healing, health and hope to the individuals and families in their care.

Home-based care is the backbone of the community response to HIV. HBC has always been and continues to be instrumental in increasing HIV testing, combatting gender-based violence, ensuring that orphaned and vulnerable children have holistic support, and rebuilding communities devastated by the HIV pandemic. HBC programs address the stigma, psychosocial realities, and discriminatory health access practices that continue to prevent or deter people from getting tested for HIV or adhering to treatment. In this way, home-based care responds to the whole person through

human connection and care by addressing social, economic, and medical barriers to testing and treatment for HIV and AIDS.

However, the real transformative power of home-based care extends beyond these practical considerations. It comes from human connection. HBC workers forge close relationships with their clients – relationships that are built on trust and are responsive to the clients' diverse and individual needs. They attend holistically to the needs of entire families and rebuild the resilience of individuals and communities. In addition, HBC workers connect their clients with other support available from community-based organizations and, increasingly, with formal health care centres. Through home-based care, community-based organizations are able to effectively join forces with the formal health system so their clients receive the best possible care to thrive.

HOME-BASED CARE & THE SLF

The earliest home-based care programs supported by the **Stephen Lewis Foundation (SLF)**, starting in 2005, were palliative. At that time, anti-retroviral (ARV) medication was not readily available on a large scale in most countries in sub-Saharan Africa, and certainly not in remote, rural regions. Community-based organizations were struggling just to cope with the devastating numbers of people contracting HIV, becoming ill, and dying, so home-based care focused on easing the pain and suffering that people experienced in their final days.

The widespread increase in access to Antiretroviral Therapy (ART) over the past decade is the great success story of the global HIV and AIDS response. It's by no means a cure, but it has radically transformed the landscape of the pandemic in sub-Saharan Africa, and it changed the primary challenge for community-based organizations from caring for the terminally ill to helping HIV-positive people maintain their health and well-being.

As access to ART increased, community-based organizations found that their home-based care programs were as important as ever. Major funding for treatment went as far as getting ARVs into government-sponsored health facilities, yet people

living in rural areas still experienced tremendous, often insurmountable, difficulty accessing medication. Significant support was still required to manage the myriad psychological and practical challenges involved in coming to terms with an HIV-positive diagnosis and successfully initiating and maintaining treatment over time. In response, many of the SLF's community-based partner organizations stepped in to fill the gap between medication and adherence. The SLF currently partners with 11 organizations for which home-based care is a key part of their HIV programming that reaches more than 50,000 people.²

2. This figure does not account for many of the family members who are served in various ways through home-based care even when they are not the formal clients. HBC workers will frequently provide various forms of assistance to the client's spouse, parents and/or children during their visits.

HOME-BASED CARE & GENDER EQUITY

Home-based care workers belong to the communities they serve. Often they have been beneficiaries of the SLF's programs in the past and have been affected by HIV and AIDS in some way. Additionally, of the more than 5,000 home-based carers that our partners work with, approximately 70% are female.³

The path towards becoming a HBC worker usually starts with being an active recipient of support from the community-based organization in some way, such as belonging to a mutual support group for people living with HIV (PLWH) or participating in an income-generating or savings and loans project. As their own lives stabilize, and their connection to the organization strengthens, these former beneficiaries start looking for ways to support their neighbours. Many HBC workers say they feel this work is their calling, and the deep, enduring commitment they bring to every household they visit plays an essential role in the transformative power of home-based care. The personal relationships they develop with their clients need to be strong, given the multiple, complex and sensitive issues they are trying to address: stigma and rejection within the family, the daunting challenge of starting ARV treatment and

then maintaining it over the long term, a host of other physical challenges, legal issues, violence, poverty and food scarcity, and complex family dynamics.

Home-based care services at ROM are mainly offered by expert clients ... who live within the same communities as the clients they follow up with and monitor. We have learned that it is easier for clients to open up their homes and their lives to other clients. Our community health workers are peers who have gone through the same experience as the clients that they support - they understand their lives and challenges best. Those we select are the ones who have achieved good treatment adherence and are knowledgeable and can lead by example. Some of our M2M (Mothers to Mothers programme) health workers have given birth to HIV negative children themselves, and it is a joy to see them support other mothers.

- Reach Out Mbuya (ROM), Uganda

3. There is significant variation from organization to organization in number of home-based caregivers they have. Our larger partners often report hundreds of HBC providers, while small organizations may report fewer than 10. What is constant is the gender differential, with women being much more likely to be the ones providing home-based care than men, no matter the organization's size.

Being home-based care workers, providing a vital and respected service in the community, and taking part in professional development trainings offered by community-based organizations, enhances the confidence and leadership skills of HBC workers themselves. The (mainly) women who engage in this work develop confidence in their ability to advocate for the health and rights of not only their clients, but also for themselves and for other women in their communities. The relationships home-based carers build with their clients give them insights into the lives and experiences of women living with HIV in their communities, helping them support women through a variety of challenges they face rooted in gender inequality, such as gender-based violence. Maasai Women Development Organization (MWEDO), in Tanzania, shares one of the ways this plays out among their home-based carers:

Our carers make sure that information about health and HIV reaches the community. Their work started in the clients' homes but then as people got to know what the carers were doing, it steadily expanded to them engaging more publicly. Now they do education at the household level and also at the village level, speaking at church gatherings, in the market places or at meetings where the village leaders gather. Through their education efforts, the women carers have gained confidence. In the past, it was rare for women to speak up in the company of men, especially on a topic like HIV. It would have been taboo. The carers are proud to be associated with MWEDO,

and they are seen as professionals and acknowledged. People listen to them because they are connected to a trusted organization. The women now speak with confidence about issues that in the past they could only address in secret.

In the context of the gendered division of labour and gendered nature of women's community and family care role and responsibilities, it is important to emphasize that, despite the skilled nature of the work, it is rare for HBC workers to receive salaries unless salaries are funded by large grants. This is beginning to change in some countries, such as Uganda⁴, however, the majority of the SLF's partner organizations rely on volunteer HBC workers and are generally only able to provide small cash stipends to fund travel expenses and other allowances, such as mobile airtime. Smaller organizations are often left in the position of not having any way to provide their care workers with cash remuneration.

To supplement their income, many HBC workers participate in a community-based organization's income-generating activities and savings and loans groups. Organizations continually seek to find innovative ways to compensate their care workers. They have found that the different training and learning opportunities they provide to workers are highly motivating and good for sharpening their practical skills. However, as our grassroots partners know, paying women for work – especially traditionally unpaid caring work – contributes to gender equality and

4. In 2018, the Ugandan Ministry of Health announced the creation of a new cadre of providers called Community Health Extension Workers (CHEWs), who will work with and supervise existing Village Health Team (VHT) workers and other types of volunteer health workers. See: [Uganda Takes Major Steps to Professionalize Community Health Workforce](#).

supports building healthy and resilient communities. For example, unpaid work performed by women and girls leaves them **less time for education, employment, civic and political engagement, and leisure**⁵. Furthermore, according to the Clinton Global Initiative, **women reinvest 90% of their income back into their families** to support things like nutrition, education, and health care, while men reinvest only 30-40%. These are among the reasons why the SLF prioritizes flexible, core funding including salaries for staff.

We know that staff and volunteers are an organization's greatest asset, and we know that by investing in women, we have a greater chance at achieving the **Sustainable Development Goals** (SDGs). Through increased opportunities for paid work for women, entire communities and nations will be better placed to lift themselves out of poverty. In this way, supporting home-based care work is in direct alignment with the SDGs, including achieving good health and well-being⁶ and quality education, and also with the Canadian **Feminist International Assistance Policy (FIAP)** goals of gender equality, poverty alleviation, and inclusive governance through women's political participation.



Swaziland Nurses Association, Eswatini, Photo by Claudia Ramos

5. **Growth and Economic Opportunities for Women (GrOW)**, International Development Research Centre, p. 1.

6. **Including target 3.3**: By 2030, end the epidemics of AIDS, tuberculosis, malaria and neglected tropical diseases and combat hepatitis, water-borne diseases and other communicable diseases.

HOLISTIC & CLIENT-CENTRED CARE

More than anything else, it's the human touch and personal connectedness that makes home-based care so remarkably effective. The carers build relationships of trust that allow families to feel comfortable talking about their experiences. The consistency of always connecting with one carer is tremendously important because it means that the family does not have to continuously disclose their issues to multiple people. Over time, as one home-based carer explained, “you become a friend” and confidant.

The organizations' deep connections to their communities also play a crucial role in helping people open up to care. As one of MWEDO's clients in Tanzania observed, “We trust MWEDO. Their work is our work; we see our own people working at the organization so we know that they take our needs to heart.” With a high level of trust established, clients are willing to embrace the services and support offered to them. Home-based carers are able to play a critical role in getting people onto ARV treatment and then monitoring their ARV adherence and progress. Many carers are also able to collect and deliver medication directly to their clients, conduct viral load tracking and index testing. As a client's health and well-being returns, the future begins to look brighter.

Home-based care allows us to deliver comprehensive, holistic care to the community. When our home-based care team visits, treatment for illnesses affecting the members of the household is done. HIV tests are also done at the household level, along with counselling, psychosocial support, hygiene support, parenting dialogues to guide grandmothers with parenting challenges, and children protection dialogues to support grandmothers through creating awareness on how to access services, such as the police to address any protection issues. The team provides career guidance support when there is a youth in the house. - St. Francis Health Care Services, Uganda

As important as monitoring and follow-up is to ARV adherence and overall health, multiple obstacles to treatment adherence often exist that have nothing to do with the medicine itself. Home-

based care visits provide the opportunity to identify the stresses, family issues, and constraints that could impede adherence. For instance, the initial reason for a visit may be to check up on a client's progress,

but soon the client starts opening up about difficulties with children, the need for school assistance, or another family member's refusal get tested or take treatment.

COMBATTING STIGMA & DISCRIMINATION

Communities that have historically been excluded, including people living with HIV, LGBTIQ peoples, sex workers, and ethnic and linguistic minorities, are generally very poorly served by mainstream health care facilities and their members often encounter a great deal of discrimination from government staff. Home-based care delivered by members of the community for their community provides much more welcoming and inclusive support. For instance, MWEDO explains their approach to working with the Maasai community in Tanzania:

Maasai people have experienced discrimination in government services, with health providers not speaking their language ... MWEDO, in contrast, is welcoming. There are no language barriers between the carers and their clients, as well as our other staff, and there's a friendliness, warmth and welcome in our approach that makes our services work so effectively. The government usually chases away the Maasai's traditional birth attendant when they bring women in to give birth at health facilities. But MWEDO sees the traditional birth attendants as important

players in caring for people, and our home-based carers work closely with them and value their contribution.

Home-based care workers also help to overcome the stigma and ostracization that far too many HIV-positive people face. The willingness of carers to be in close physical and emotional contact with PLWH contributes to breaking down stigma and restoring emotional well-being. In addition, over time, HBC workers often facilitate enhanced family understanding, support, acceptance and, at times, reintegration. In this way, home-based care workers create an enveloping support structure that has enormous benefit for HIV-positive people who are living with very high levels of stress. The combination of better physical health through treatment and nutrition, better emotional health through improved family relations, and better economic health through income generation, helps to re-establish hope and meaning in people's lives. Clients feel much closer to their families and their communities, and many ultimately proceed to become care workers themselves.

LINKING TO COMMUNITY-BASED SERVICES



Swaziland Nurses Association, Eswatini,
Photo by Claudia Ramos

Home-based care is also a vital entry point for direct assistance. One of the most important contributions made by HBC workers is the way in which they connect people to the other forms of support available. For example, nutritional deficits are a frequent obstacle to overall health and to treatment adherence, so home-based caregivers often connect their clients with the organization's direct food support and provide guidance on food preparation and how to plant vegetable gardens. Furthermore, to address the economic pressures that people living with HIV often face, carers may connect clients and their families to income generation and training opportunities, often operated by the community-based organization.

A lot of our beneficiaries complain about being unable to keep on their treatment due to insufficient food or unbalanced food. The team trains the family on how to improve food security for the home, and in many cases food parcels are also delivered. In every home visit that we carry out, the team will monitor the progress of those who are taking ARV medication. They look at their viral loads (based on the feedback we get from the hospitals), their physical health and appearance, their spiritual health, and their emotional and psychological well-being – and they help them to get extra professional support where they see it is needed to keep the person on treatment.

- Kimara Peers, Tanzania

Home-based care can also be an essential step in the journey to initiating treatment. HBC providers can help to identify individuals who are resistant to being tested or starting treatment and connect them with peer support programs. For instance, Siyanqoba in South Africa runs a 'Man to Man' project that engages with men in the community to deal with the specific obstacles they face in coming to terms with the reality of HIV and the need to protect their health, to get tested, and to maintain the discipline needed to stay on treatment. Siyanqoba explains the direct link they have made between this project and home-based care:

When home-based carers identify issues in the home they will request support and intervention from the Man to Man project. Our coordinator says that "it's the home-based care that creates access for us and makes the project work." The home-based care providers call in the Man to Man facilitators if they are experiencing a problem that a male counsellor could best resolve. There are times when men can be resistant to getting tested or taking treatment. Many men want to just rely on their partners' HIV test results and assume that their results are the same. The Man to Man project encourages men to test on their own to confirm their own status.



Catholic AIDS Action Namibia, Namibia, Photo by Alexis MacDonald





Providing routine vaccinations



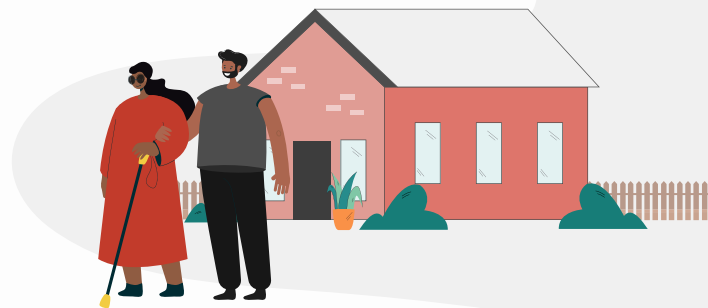
Educating on health



Monitoring ARV adherence and wellness



HBC worker



Delivering nutritious food



Bathing clients and delivering medicine



Post partum support



PARTNERING WITH LOCAL GOVERNMENT

The widespread availability of ARVs has brought about a significant improvement in the interaction between community-based caregivers and government-sponsored health providers. The challenges involved in getting people onto treatment and keeping them there are quite daunting and a client's chances of successfully maintaining their treatment over time improve significantly when they are connected with both the formal health care system and a supportive local organization.

While some community-based organizations continue to struggle for meaningful recognition, many are increasingly seen as a key partner of governments when it comes to HIV treatment and adherence. In many cases, this has led to the development of mutually supportive and productive relationships. "We work as partners with each other," says mothers2mothers International (m2m) in Lesotho. And, Swaziland Positive Living (SWAPOL) in Eswatini reports, "There is no gap between the clinics, the hospitals and us."

Siyanqoba explains how these partnerships are key to successful HIV treatment initiation and adherence:

It's the home-based care providers who are really linking people up with the government services, and it's our work that actually makes what the government is providing effective. The government doesn't have any community outreach services beyond the occasional

mobile clinic. It's our home-based carers who are monitoring people's adherence to make sure they don't fall off their medication, tracing people who have defaulted and convincing them to start treatment again, providing psycho-social support and helping people to improve their nutrition so that the medication will be able to work. It's our carers who are actually spending real time with the clients and so we're able to share information and provide education in a way the government staff just can't. Some of the health facilities hire their own community workers, but these people just focus on awareness raising - they certainly don't do what we are doing, bathing people, feeding them, helping them find employment and training opportunities, making their medical appointments and checking up to be sure that they've gone to their appointments.

In the past, the relationship between health officials and our community-based caregivers was not always good, and our caregivers were not viewed as equal partners in addressing HIV. This has now shifted and our caregivers and



3- Kitovu Mobile, Uganda, Photo provided by Kitovu Mobile

the health facility staff work well together and value one another's roles and contributions. Our caregivers provide the health facility workers with necessary information about what's going on in the local community. The health facility will connect new patients up with our caregivers so that they can monitor their treatment, and our caregivers will link community members back to the health facilities for referrals for testing or treatment. Our caregivers now have the authority to collect medication from the facilities on behalf of our clients, which is just one indicator of the trust that has been established between the government service providers, our caregivers, and the community.

Many community-based organizations do not distribute ARV medications themselves and instead refer their clients to government health facilities for treatment. In turn, the health facility

will refer clients to community-based organizations to provide the kind of wrap-around, ongoing support that the health facility is not equipped to provide. As they gain more recognition and respect from government health programs, community-based organizations are able to influence some of the practices at health facilities. Kimara Peers, for instance, was involved in a research project investigating stigma in health facilities and the impact it was having on treatment initiation and adherence. As a part of that work, they participated in trainings with health facility staff on the benefits of friendliness and warmth in service delivery. Not only was that government department receptive to their input from the community, but they have been invited by other facilities to replicate the approach. Siyanqoba shares a similar experience of relaying community concerns to government departments:

In the past, the health facilities would treat people living with HIV in separate spaces that were set aside in their clinics. This created stigma and discouraged people from seeking care for fear of disclosure because their presence would be noticed. Our home-based care workers intervened, and now all chronic patients are treated in the same area. They see themselves as the voice for the problems experienced by the users of government services.

The effectiveness of these formal and informal partnerships with governments is perhaps the most promising finding in our review of our home-based care partners. Community-based organizations are playing an absolutely critical role in the creation and growth of continuous chains of care, linking people living in remote rural communities, not only with the services provided by the organizations themselves, but with the various forms of medical assistance that are available from government sponsored health facilities.



Mothers2Mothers Lesotho, Lesotho, Photo by Ryan Tantuan

HOME-BASED CARE & COVID-19

In addition to the challenges posed by HIV and AIDS, the ongoing global COVID-19 pandemic poses an additional major public health threat throughout the African continent, putting immense pressure on already overstretched and under-resourced health systems. With increased lockdowns or restrictions in many countries, access to food and medicine continues to be limited, and underfunded health systems remain under strain.

At the time of writing, many of the SLF's partners are experiencing a difficult third wave of the pandemic amidst vaccine shortages. The Africa Centre for Disease Control and Prevention aims to vaccinate **60% of the African continent by the end of 2022**, which is more than a year-and-a-half after similar targets in many other parts of the world. As such, the COVID-19 pandemic in Africa does not have an end in near sight.

Community - based organizations delivering home-based care provide a lifeline to people affected by HIV and AIDS because of their tangible connection to evolving community needs. They are the critical and reliable support systems that vulnerable communities need during COVID-19. Community-based organizations have the established networks of care and trust needed to reach their most

vulnerable community members. Additionally, their experience responding to the AIDS pandemic has given them the expertise, agility and creativity to respond to this crisis that - like AIDS - is gendered and disproportionately affects women and girls. This sentiment is echoed in a recent UNAIDS report: "The huge cadres of community health workers ... and revived community health systems are unique contributions of the HIV response which are now also playing important roles in the response to the COVID-19 pandemic."⁷

This case for support comes at a significant moment in the history of the response to HIV and AIDS, 40 years after the emergence of the first cases of HIV. On one hand, the number of people accessing anti-retroviral therapy globally is at an all-time high, having tripled since 2010.⁸ On the other, the global community and the

7. Pan Caribbean Partnership Against HIV/AIDS (PANCAP), **Global AIDS Strategy 2021-2026, End Inequalities, End AIDS**, p.22

8. At the end of 2019, two-thirds of HIV-positive people (an estimated 25.4 million of 38 million) were taking ARVs. UNAIDS, **Global AIDS Update 2020 Report**, p.13.

vast majority of individual countries have missed the treatment goals of 90-90-90 by 2020⁹ at the same time that the COVID-19 pandemic threatens to undermine decades of progress made on access to HIV testing, treatment, and care.¹⁰

Disruption in access to treatment and to prevention commodities such as condoms and lubricants, reduction of uptake and consistent use of PrEP (pre-exposure prophylaxis), increased gender-based violence, delays in testing and treatment initiation to prevent vertical transmission (i.e. mother-to-child transmission), and increased discrimination against LGBTIQ communities and sex workers are threatening to undo decades of progress made in the HIV and AIDS space.¹¹ According to the UN, “The impact of the COVID-19 pandemic on the HIV response could result in 123,000 to 293,000 additional HIV infections and 69,000 to 148,000 additional AIDS-related deaths globally.”¹²

Despite this, preliminary reports suggest that treatment access numbers are remaining relatively consistent in many countries despite COVID-19.¹³ This is due in part to community-based organizations that have been able to swiftly pivot and adapt to their new realities, while continuing to provide critical home-based care services and ensuring that those most at risk of contracting COVID-19 continue to receive vital health services and support.

HBC workers play a critical role in educating their communities on COVID-19 prevention, increasing vaccine access, providing psychosocial support during this challenging time, and identifying and supporting women and girls at risk of or experiencing gender-based violence. This is particularly important, as the most recent data indicates that people living with HIV are at increased risk for severe outcomes associated with COVID-19, including mortality, compared with people without HIV.¹⁴ Moreover, the **shadow pandemic** of violence against women and girls is further putting them at risk of contracting HIV. For these reasons, the SLF and our grassroots partners understand the critical need for home-based care not only in response to the current HIV and AIDS and COVID-19 pandemics, but also for future pandemics. By strengthening HBC systems, our grassroots partners across sub-Saharan Africa can also safeguard against future pandemics.

9. 90-90-90 refers to 90% of HIV-positive people knowing their status, 90% of people diagnosed HIV-positive accessing sustained ARV treatment, and 90% of people on treatment having achieved viral suppression. According to UNAIDS, by end of 2019, there were 5.4 million people globally who still needed sustained access to ARVs resulting in viral suppression to achieve the 90-90-90 targets. Only 14 countries globally had reached those targets, including two in sub-Saharan Africa. See UNAIDS, **Global AIDS Update 2020 Report**, p.13.

10. Ibid, p.35.

11. Ibid, p.28-33.

12. United Nations, **Report Addressing inequalities and getting back on track to end AIDS by 2030** (March 13, 2021), p.23.

13. UNAIDS, **Global AIDS Update 2020 Report**, p.28.

14. UNAIDS, **End Inequalities. End AIDS. Global AIDS Strategy 2021-2026**, (2021), p.25.

AN ON-GOING & URGENT NEED

As the global AIDS community continues to deal with the impacts of the COVID-19 pandemic as well as the reality of missing the 90-90-90 targets, it is essential to acknowledge, focus on and strengthen the programs and strategies that can effectively reach communities that are often the hardest to reach. By the end of 2019, the global community was 5.4 million people short of meeting the 90-90-90 goals for treatment initiation and treatment adherence.¹⁵ Reflecting on those figures, UNAIDS argued, “Linkage to care represents the single greatest challenge to achieving the 90-90-90 targets”¹⁶ and confirmed, “Reaching large percentages of the people in greatest need requires a community-based and community-led approach.”¹⁷

As the global community moves beyond the missed 90-90-90 targets to the new targets of 95-95-95 for 2025, we must prioritize reaching communities which have been systematically excluded. Home-based care programs have had remarkable success in reaching people living with HIV in rural and underserved communities, linking them to care, and supporting them to maintain treatment. More than a fifth of the SLF’s partners that provide home-based care are reporting 100% treatment adherence rates for their clients, **more than half** are reporting adherence rates above 95%, and every single community-

based-organization supported by the SLF is reporting adherence rates **well above** the regional average.

The 2021 – 2026 Global AIDS Strategy also recognizes that community-led responses “help to reduce HIV-related inequalities by enabling the tailoring of approaches to meet the needs of the people who need services the most”¹⁸ and prioritizes “maintain[ing] and increas[ing] donor funding, including for addressing the root causes of inequalities through community-led responses.”¹⁹ A recent UN report emphasizes:

15. UNAIDS, **Global AIDS Update 2020 Report**, p.13.

16. UNAIDS, Press Release: **UNAIDS calls on countries to accelerate efforts and close service gaps to end the AIDS epidemic among children and adolescents**, (July 22, 2019).

17. UNAIDS, “**Communities at the Centre**,” (2019), p.9.

18. UNAIDS, **End Inequalities. End AIDS. Global AIDS Strategy 2021-2026**, (2021), p.51.

19. Ibid, p.49

Communities living with, at risk of, and affected by HIV are the backbone of the HIV response. Initiatives led by people living with HIV, women, key populations, young people and other affected communities have identified and addressed key inequalities and service gaps; advocated for the rights of their constituents; vastly expanded the evidence base for effective action against HIV; supported the planning, coordination and implementation of national responses and donor programs; and expanded the reach, scale and quality of health services. Communities have stepped forward in the face of the COVID-19 pandemic to provide information and personal protective equipment to vulnerable and marginalized communities, and to preserve the delivery of key HIV services. Communities also offer a critical interface within efforts to strengthen primary health care.²⁰

However, overall international HIV assistance declined by nearly 10% from 2015 to 2019²¹ and this underinvestment, according to the United Nations, is partially responsible for the failure to reach targets for 2020.²² In 2019, international investments in response to HIV in low and middle-income countries totalled US \$7.8 billion, declining by US \$165 million from US \$8 billion in 2018, even after accounting for inflation and exchange rate fluctuations. This is nearly the same as funding levels

from a decade ago, despite a 25% increase in the number of people living with HIV in low and middle-income countries.²³ It is noteworthy that Canada, while decreasing its overall official development assistance (ODA) portfolio between 2015 to 2019²⁴, also decreased its multilateral contributions specifically to the global HIV and AIDS fund.²⁵

While some progress in the HIV and AIDS funding landscape has been made recently – for example, private philanthropic investments reached a new high in 2019 – a 7% increase from 2018 – this increase is almost entirely due to one single funder.²⁶ It is also concerning that of the 264 funders analyzed by **Funders Concerned About AIDS (FCAA)** in 2019, the top 20 funders account for 92% of the year's total. This same report also shows that overall support for key populations and general operating support – the critical core support that allows community-based organizations in low-income countries to support proven community-led and implemented initiatives, such as home-based care services – has decreased since 2018.²⁷

Despite the fact that the majority of people living HIV are in low income countries, low-income countries saw a 47% drop in funding (more than \$33 million) and support for high income countries actually increased by 5%.²⁸ The ongoing global COVID-19 pandemic has further negatively

20. United Nations, **Addressing inequalities and getting back on track to end AIDS by 2030** (March 13, 2021), p.14

21. UNAIDS, **End Inequalities. End AIDS. Global AIDS Strategy 2021-2026**, (2021), p.49.

22. United Nations, **Addressing inequalities and getting back on track to end AIDS by 2030** (March 13, 2021), p.22.

23. Avert, **Funding for HIV and AIDS** (May 25, 2021).

24. Centre for International Policy Studies, **Foreign Aid Flows: The Canadian Government Is Still Not Stepping Up to the Plate** (April 20, 2020).

25. UNAIDS, **Donor Government Funding for HIV in Low- and Middle-Income Countries in 2020**, (July 2021), p.8.

26. Funders Concerned About AIDS, **Philanthropic Support to Address HIV/AIDS in 2019** (April 2021), p. 16.

27. Ibid, p. 46 and 41.

28. Ibid, p.41.

impacted the funding landscape, putting hard-fought gains made against HIV and AIDS at risk and making the need for significant new and additional investments even more urgent if we are to get the HIV response back on track.

In order to respond to the HIV and AIDS pandemic, we must focus resources on the effective interventions proven to work, close service gaps, and reach the populations in greatest need. Funders at all levels – governments, multilateral institutions, and philanthropic organizations – can demonstrate leadership in this key area of global health and development with increased support and significant new investments for community-based organizations providing home-based care.

Recovery from this crisis will extend over a number of years, and non-profits will need the support of funders to respond to changing events and circumstances. This pandemic will have long-term impacts and cannot be solved by pre-2020 contribution amounts.

– Center for Disaster Philanthropy & CANDID



Mothers2Mothers Lesotho, Lesotho, Photo by Ryan Tantuan

Investing too little, too late will not only cause the AIDS epidemic to worsen and mean that ambitious targets in the Strategy will not be met, but it will further add to the long-term costs of the HIV response.²⁹ – UNAIDS



Nancholi Youth Organisation, Malawi, Photo provided by NAYO Malawi

29. UNAIDS, *End Inequalities. End AIDS. Global AIDS Strategy 2021-2026*, (2021), p. 59-60.

67%

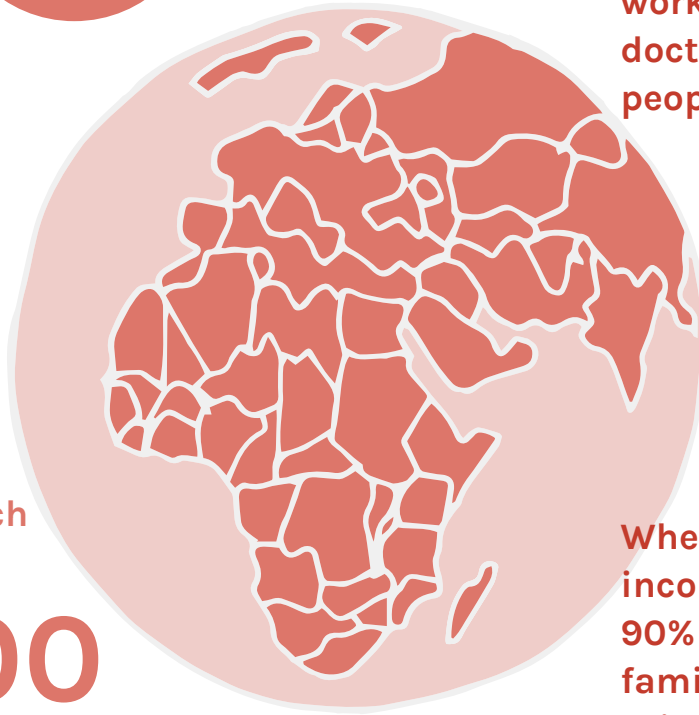
of people living
with HIV are in
sub-Saharan Africa

In 10/
15

Only
3%

of global health
workforce is in
this region

countries where the SLF
works, there is only one
doctor for every 10,000
people



SLF's 11 partner
organizations reach
more than

50,000

people with home-based
care as part of their HIV
programming

When women earn
income they invest
90% back into their
families to support
things like nutrition,
education and
healthcare

70%

SLF's partners
work with more
than 5,000 HBCs;
70% of them are
female

According to the UN,
COVID-19 could result in

123,000 to
293,000

additional HIV infections
and 69,000 to 148,000
additional AIDS-related
deaths

International
HIV assistance
declined by nearly

10%

between 2015
and 2019

CONCLUSION

Community-based organizations in sub-Saharan Africa are reporting tremendous successes in the prevention and treatment of HIV and AIDS due to two factors: 1) home-based care enables them to reach greater numbers in remote, rural areas who would otherwise be left without assistance for HIV; and, 2) they are providing a holistic form of care that is effective in addressing the variety of issues that affect adherence and helps to improve people's resilience.

The care that CBOs are providing for people in their communities is generating an even greater capacity for these communities to care for themselves. Community-based programs are making the ARV medication their governments and international funders have invested in supplying infinitely more effective. Increasing the numbers of people who initiate ARV treatment is an important milestone in the fight against HIV, but the end goal and real victory is to increase the number of people who are maintaining their treatment over time and go on to live full and healthy lives. In large measure, that goal is being achieved because of the contributions made by home-based care programs.

Home-based care has become an essential part of the solution to the HIV and AIDS pandemic in sub-Saharan Africa. The real question now is how it will be funded. Government-sponsored health facilities are increasingly recognizing the importance of CBOs' contribution, as evidenced by their greatly improved working relations

with these organizations, the consistent development of mutual referral networks, and the integration of the CBOs' home-based care providers into many aspects of the facilities' own operations. Unfortunately, this recognition has not yet translated into national governments increasing the financial resources they are willing to provide to community-based groups.

In many ways due to the ongoing COVID-19 pandemic, the international HIV and AIDS response community now has a greater understanding of and respect for the effectiveness and efficiency of community-led and implemented responses. However, it remains to be seen how this interest will translate into program funding. The biggest players - organizations such as PEPFAR that implement massive, multi-million dollar programs - are not currently discussing increasing their financial support to community-based organizations. Instead, they're discussing ways they can pick up on some of the



Nancholi Youth Organisation, Malawi,
Photo provided by NAYO Malawi

CBOs' ideas and then try to integrate them into their own programs, directed by their headquarters and implemented by international staff.

But it really matters *who* does this work. We hope this report makes clear that the CBOs have not only figured out a key part of the HIV and AIDS puzzle, but that the solution they have found is dependant on the role that CBOs themselves play in and for their own communities. The community-based response cannot be mechanically applied by anyone, anywhere. There's a real magic in how it works and this is the magic of the local people who 'have home-based care in our veins'. The human connectedness that CBOs can uniquely mobilize is a critical piece of this work. The big challenge in the coming years will be to bring additional large and influential HIV and AIDS funders on board.

This report demonstrates the profound impact of home-based care for communities across sub-Saharan Africa; its critical importance in the fight against HIV and AIDS, for gender equality, and for healthy, resilient communities; and its ability to safeguard against future pandemics. We hope that it galvanizes political will and action for funders at all levels to demonstrate leadership in this key area of global health and development by increasing current levels of support and making significant new investments for home-based care. In doing so, funders will directly support national and international development priorities including the FIAP and the Sustainable Development Goals.

GLOSSARY OF ABBREVIATIONS

ARV	Antiretroviral Medication
ART	Antiretroviral Therapy
CBO	Community-based organization
CHEW	Community Health Extension Worker
CHW	Community Health Worker
FIAP	Feminist International Assistance Policy
HBC	Home-based care
ODA	Official Development Assistance
PLWH	People living with HIV
SDGs	Sustainable Development Goals
SLF	The Stephen Lewis Foundation
VHT	Village Health Team Worker

