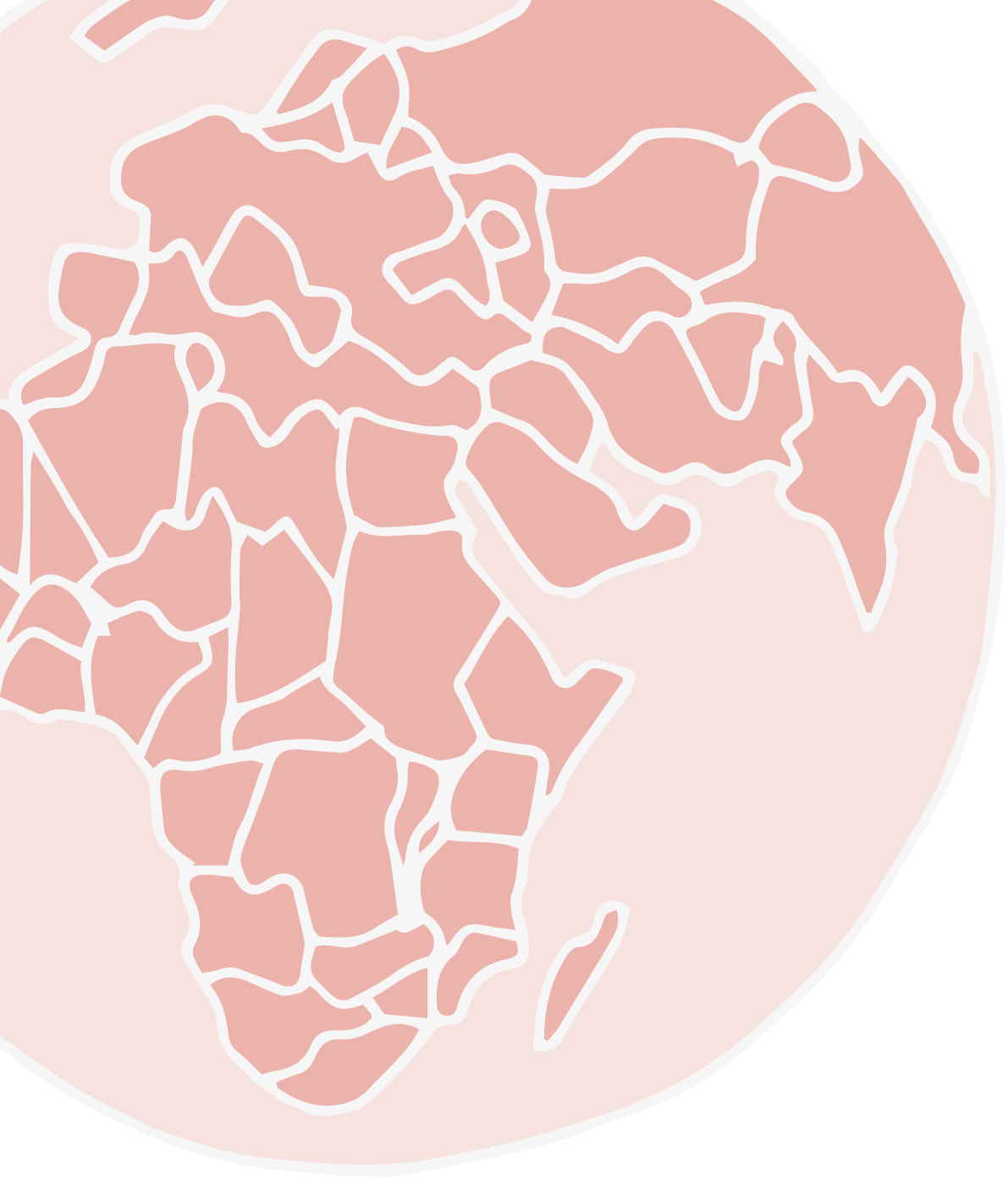
the Stephen Lewis FOUNDATION

Healing, Health, and Hope

Prioritizing Home-Based Care and Community-Based Responses to HIV and AIDS



Stephen Lewis Foundation
260 Spadina Ave., Suite 100,
Toronto, ON, Canada M5T 2E4
Tell: +1 416-533-9292 Toll Free: 1-888-203-9990
Email: info@stephenlewisfoundation.org
www.stephenlewisfoundation.org
Charitable Registration # 89635 4008 RR0001

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CONTENTS

Umdoni and Vulamehlo HIV/AIDS Association, Uganda, Photo by Alexis MacDonald

INTRODUCTION

WHAT IS HOME-BASED CARE?

Home-based care (HBC) is a community-based approach that reaches people both where they are physically located and where they feel most safe — their homes and their local communities. Home-based care is a key part of the community-based response to the HIV and AIDS pandemic in sub-Saharan Africa.

Home-based care workers deliver care to communities and individuals who would otherwise be missed by centralized health care systems. While sub-Saharan Africa is home to 67% of all people living with HIV worldwide,[1] the African region as a whole has just 3% of the global health workforce (defined as doctors, nurses, and midwives).[2]

In fact, in 13 of the 15 countries where the SLF works, there are fewer than three doctors for every 10,000 people, far below the global average.[3]

In rural communities with limited formal health care infrastructure and/or cost-prohibitive transportation options, home-based care workers can reach socially-marginalized and geographically-isolated community members. In addition, by delivering health care in a client's home, HBC workers reduce the impact stigma can have on a person's willingness to access services, and increase the safety and comfort a client feels in opening up and sharing their struggles. Where national health systems fail to reach people, community-based organizations (CBOs) are filling the gaps and consistently serving their communities through home-based and community-based care.

This report documents the impact and insights of 40 SLF partners who have been delivering powerfully effective and holistic home-based care programs for over a decade in 13 countries where the SLF operates. These organizations reach more than 50,000 people annually.[4]

1. UNAIDS, "**Global AIDS Update: Confronting Inequalities – Lessons for Pandemic Responses from 40 Years of AIDS**" (Geneva, 2021), 12.
2. World Health Organization, "**The World Health Report 2006: Working Together for Health**" (Geneva, 2006), 8.
3. The global average is 17.5 doctors per 10,000 people. In the Americas Region, that number is 28.4 and in the European Region it's 43.2. World Health Organization, "**World Health Statistics 2021: Monitoring Health for the SDGs**" (Geneva, 2021), 98-104.
4. 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.

Swaziland Nurses Association, Eswatini, Photo by Claudia Ramos

“Where national health systems fail to reach people, community-based organizations (CBOs) are filling the gaps and consistently serving their communities through home-based and community-based care.”

FROM HOME-BASED CARE TO COMMUNITY-BASED CARE

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. Home-based care focused on easing the pain and suffering that people experienced in their final days.

Over the past decade, the widespread increase in access to Antiretroviral Therapy (ART) 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 around the world. It changed the primary challenge for community-based organizations from providing dignified care for the terminally ill in their final days at home to helping people living with HIV maintain their health and well-being in a supportive community environment.

As access to ART increased, community-based organizations found that their home-based care programs were as important as ever, and needed to expand. 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.

Today, home-based care extends beyond the home and has become an essential component of community-based care systems. It is instrumental in increasing HIV testing, combatting gender-based violence, ensuring that orphaned and vulnerable children access education and 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 has become an entry-point to complex community-based responses. It responds to the whole person by providing care that addresses the social, economic, and medical barriers to testing and treatment for HIV.

However, the real transformative power of home-based care extends beyond practical considerations. It comes from human connection. HBC workers forge close relationships with their clients — relationships built on trust. They tune into clients' diverse and individual needs, as well as 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 government services. Through home-based care, community-based organizations join forces with the formal health and social service system so their clients receive the best possible opportunities to thrive.

WHO ARE HOME-BASED CAREGIVERS?

The vast majority of home-based care workers are women.[5] With some variation depending on the country and context, home-based care workers are generally trained community members. Several 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). They are mostly volunteers and many are living with HIV themselves. HBC workers visit countless homes each day, travelling great distances, most often on foot or by bicycle. They dispense drugs and food, make referrals, and provide peer support and counselling. They bathe their clients and carry out household chores. They ensure children's 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 caregivers form the backbone of the community response to HIV.

The path towards becoming an HBC worker often starts with being an active recipient of support from the community-based organization in some way, such as by belonging to a mutual support group for people living with HIV or participating in an income-generating or savings and loans program. As their own lives stabilize, and their connection to the organization strengthens, these former beneficiaries start looking for ways to support their neighbours.

"Above all, they provide a vital service by delivering healing, health and hope to the individuals and families in their care. Home-based caregivers form the backbone of the community response to HIV."

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; as well as legal issues, violence, poverty and food scarcity, and complex family dynamics.

5. Of the more than 5,000 home-based carers that our partners work with, approximately 70% are women. This is consistent with figures cited by the International Labour Organization, which reports that 68% of community health workers in sub-Saharan Africa are women. International Labour Organization, "**ILO Calls for Urgent Action to Prevent Looming Global Care Crisis**" (Geneva, 2018).

Swaziland Nurses Association, Eswatini, Photo by Claudia Ramos

"Home-based care services at Reach Our Mbuya (ROM) are mainly offered by expert clients (both adults and adolescents) who live within the same communities as [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 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 Community Health Initiative, Uganda

Providing a vital and respected service in the community and taking part in professional development training offered by community-based organizations enhances the leadership skills of HBC workers. The (mainly) women who engage in this work develop confidence in their ability to advocate for the health and rights of their clients, themselves, and other women.

Maasai Women Development Organization (MWEDO), Tanzania, Photo by Alexis MacDonald

HOME-BASED CARE WORK— UNDERPAID AND UNDERVALUED

Home-based care work is underpaid and undervalued in large part because it is gendered work. Home-based care work, whether done by women or not, is caregiving labour – labour that is generally seen as women's work and fits within the context of the gendered division of labour in families, communities, and society-at-large.[6]

Despite the skilled and critical nature of home-based care work, it is rare for HBC workers to receive payment at all, except for limited instances where compensation is funded by large grants or government departments. This is beginning to change in some countries, such as Uganda;[7] however, the majority of the SLF's partner organizations rely on volunteer HBC workers and can only provide small 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 financial remuneration.

"Unpaid work performed by women and girls leaves them less time for education, employment, civic and political engagement, and leisure."

6. For a more fulsome discussion of the gendered nature of caregiving labour in the context of the HIV pandemic in sub-Saharan Africa, see UNESCO, "**The Implications of HIV and AIDS on Women's Unpaid Labour Burden**" (Paris, 2010).
7. 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. IntraHealth, "**Uganda Takes Major Steps to Professionalize Community Health Workforce**" (Chapel Hill, United States, 2018).

To supplement their income, many HBC workers have to participate in a community-based organization's income-generating activities and savings and loans groups in addition to doing their own household labour and providing home-based care throughout the community.[8]

"As part of the national response, and consistent with the practice in other parts of Africa, there has been a shift in the model of care for people living with HIV and AIDS from hospital care to home-based care. While this practice has partly helped to reduce pressure on public hospitals that do not have adequate staff and space to care for HIV and AIDS patients, it is done with the assumption that there is adequate community and family support to meet the patients' needs. The reality is that with about 91% of HIV and AIDS support caregivers in South Africa being women, home-based care has significantly increased the burden of care for many women."

- Sophiatown Community Psychological Services, South Africa

Without adequate funding to support HBC worker salaries, community-based organizations work to find meaningful ways to compensate their care workers. They have found that the training and learning opportunities they provide are highly motivating and good for sharpening practical skills. However, getting paid equitably for work is a human right.[9] In addition, as our grassroots partners know, paying women for their work – especially traditionally unpaid caring work – contributes to gender equality and builds healthy and resilient communities. Unpaid work performed by women and girls leaves them less time for education, employment, civic and political engagement, and leisure.[10]

8. The findings of the Huairou Commission, which consulted home-based caregivers in 13 countries in Africa, reflects similar trends to those identified by the SLF in our review of our community-based partners' reports: home-based care is rarely paid and, in fact, home-based care workers often incur transportation and other costs to carry out their work. Shannon Hayes, "**Valuing and Compensating Caregivers for their Contributions to Community Health and Development in the Context of HIV and AIDS: An Agenda for Action**" (New York, Huairou Commission, 2010).
9. See, for example, article 15 of the **African Charter on Human and Peoples' Rights**, that reads: "Every individual shall have the right to work under equitable and satisfactory conditions, and shall receive equal pay for equal work."
10. Mary O'Neil, Alejandra Vargas, and Deepta Chopra, "**Unpaid Care and Women's Empowerment: Lessons from Research and Practice - Policy Brief**" (Ottawa, International Development Research Centre, 2017).

HOLISTIC AND CLIENT-CENTRED CARE

The gendered nature of home-based care may be largely responsible for it being underpaid work, but it may also be one of the reasons for its effectiveness. Home-based care workers bring emotional intelligence to their caregiving — listening, empathy, personal connectedness, and human touch, and the recognition that the situation of any one individual is intrinsically connected to their wider social environment.

These skills are often undervalued in more traditional work environments.[11] The most effective HBC workers build relationships of trust that allow entire families to feel comfortable sharing their experiences, which in turn allows caregivers to tailor support strategies. Over time, as one home-based carer explained, "you become a friend" and confidant.

While trust in individual home-based caregivers is essential, so is trust in the organizations for which those caregivers work. Community-based organizations' deep connections play a crucial role in helping people open up to care.

As one of Maasai Women Development Organization (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 play a critical role in getting people onto ARV (anti-retroviral) treatment and then monitoring their ARV adherence and progress. Many carers collect and deliver medication directly to their clients, conduct viral load tracking (monitoring the amount of HIV infection

11. Ruth Needleman and Anne Nelson offer an explanation of this in their chapter in The Worth of Women's Work. In particular, they explain, "If women perform certain work 'naturally' with no special training or skill, then women's work could conceivably be handled by anyone. This seems to be the conclusion that many employers draw.... Views such as these contribute to the undervalued status of women's occupations in the labor market.... Women's ability to manage social relations is rarely if ever acknowledged as a skill. Even though this talent seems to have a direct and positive effect on productivity ... it, too, is discouraged and devalued. It is often seen as 'natural' for women, hence not part of the job, certainly not something to be rewarded." Ruth Needleman and Anne Nelson. "Policy Implications -- The Value of Women's Work" in The Worth of Women's Work: A Qualitative Synthesis, ed. Anne Statham, Eleanor M. Miller, and Hans O. Mauksch (Albany: State University of New York, 1987), 295.

Reach One Touch One Ministries (ROTOM), Uganda, Photo provided by ROTOM

in a person's blood) and index testing (reaching out to close contacts of clients living with HIV in order to extend HIV testing and counselling). 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, [and] parenting dialogues to guide grandmothers with parenting challenges. ... 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 are 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 to get tested or take treatment. As representatives of community-based organizations, home-based caregivers are well-positioned to support clients and their families in accessing community programs that address these concerns.

COMBATTING STIGMA & DISCRIMINATION

Communities that have historically been marginalized, including people living with HIV, LGBTIQ people, sex workers, people with disabilities, and ethnic and linguistic minorities, are generally very poorly served by mainstream health care facilities and often encounter a great deal of discrimination from staff who are untrained in their needs. Home-based care delivered by members of the community for their community provides much more welcoming and inclusive support. For instance, Maasai Women Development Organization (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's medical facility, 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. Hospital personnel usually chase 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."

- Maasai Women Development Organization, Tanzania

"The combination of better physical health through treatment and nutrition, better emotional health through counselling and improved family relations, and better economic health through referral to other related CBO programming, helps to re-establish hope and meaning in people's lives."

Home-based care workers also overcome the stigma and ostracization that far too many people living with HIV face. The willingness of carers to be in close physical and emotional contact with people living with HIV contributes to breaking down stigma and restoring emotional well-being. In addition, over time, HBC workers can 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 benefits for people living with HIV dealing with very high levels of stress.

The combination of better physical health through treatment and nutrition, better emotional health through counselling and improved family relations, and better economic health through referral to other related CBO programming, 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 OTHER COMMUNITY-BASED SERVICES

Home-based care is part of a comprehensive set of services offered by a community-based organization and often serves as an entry point for other services. For example, nutritional deficits are a frequent obstacle to overall health and treatment adherence, so home-based caregivers often connect their clients with the organization's direct food support and provide guidance on food preparation, planting vegetable gardens, or raising animals. 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 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 Peer Educators and Health Promoters Trust Fund, Tanzania

Home-based care can also be an essential step in the journey to initiating treatment. HBC providers can help identify individuals who are resistant to being tested or starting treatment and connect them with peer support programs. For instance, Siyanqoba Community Support Group in South Africa runs a Man to Man project that deals with the specific obstacles men face in coming to terms with HIV, getting tested, and maintaining the discipline to stay on treatment. Siyanqoba explains the direct link it has made between this project and home-based care:

"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."

- Siyanqoba Community Support Group, South Africa

Reach One Touch One Ministries (ROTOM), Uganda, Photo provided by ROTOM

PARTNERING WITH LOCAL GOVERNMENT

Home-based care does not replace the need for a doctor or nurse. Rather, it augments the effectiveness and accessibility of formal medical care. To ensure quality care, HBC programs need government-level support to create strong referral networks to formal health facilities and expertise.

Additionally, 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 on treatment and keeping them there are quite daunting, which is why collaboration between the formal health care system and community-based organizations is a key component of strategies to increase treatment initiation and adherence.[12]

While some community-based organizations continue to struggle for meaningful recognition, many are increasingly seen as key government partners 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 (m2m) in Lesotho. Swaziland Positive Living (SWAPOL) in Eswatini reports, "There is no gap between the clinics, the hospitals and us."

12. World Health Organization, **"Updated Recommendations on Service Delivery for the Treatment and Care of People Living with HIV"** (Geneva, 2021).

Siyanqoba in South Africa 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 psychosocial support and helping people to improve their nutrition so that the medication will be able to work.

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 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."

- Siyanqoba Community Support Group, South Africa

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 can influence some of the practices at health facilities.

Kimara Peers in Tanzania, 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 health facility staff training on the benefits of friendliness and warmth in service delivery. Not only was that government department receptive to their input from the community, they have been invited by other facilities to replicate the training.

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.

"There is a strong referral network between KIPEWA and the health centres. Our home-based care workers, who we call COVHs (community volunteers for home-based care), act as link-points between the community, KIPEWA, and the health facilities. Five of our home-based care workers are now actually attached to the government health centres.

The COHVs have a timeslot in the morning to give a health talk and help waiting clients in drug adherence, the disclosure process, and personal interaction with the COHV. This enables linkage to community KIPEWA support groups from the health centre to the community. Their attachment to the facility enables defaulter tracing and home visits, care retention, and linkages back to care for those termed as lost-to-follow-up."

- Kiambu People Living with HIV&AIDS (KIPEWA), Kenya

Catholic AIDS Action, Namibia, Photo by Alexis MacDonald

Reach One Touch One Ministries (ROTOM), Uganda, Photo provided by ROTOM

COMMUNITY-BASED CARE AND COVID-19

Organizations delivering community-based care, including home-based care, provide a lifeline to people affected by HIV and AIDS because of their tangible connection to evolving community needs. The immense value of this authentic connection has never been more apparent than in the face of the ongoing COVID-19 pandemic. COVID-19 has laid bare the limitations and vulnerabilities of more traditional heath facilities and has heightened the need for more decentralised health responses. Now, more than ever, CBOs are needed for the critical and reliable role that they play in communities recovering from multiple impacts of the COVID-19 pandemic.

Community-based organizations have the established networks of care and trust required to reach the most marginalized community members. Their depth of experience in responding to the AIDS pandemic grounds the expertise, agility and creativity with which they are responding to this ongoing crisis which, like the AIDS pandemic, 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."[13]

COVID-19 has put immense pressure on the already overstretched and under-resourced health systems of countries across sub-Saharan Africa, which have a combined population of approximately 1 billion people. While approaches to addressing the pandemic have differed from country to country, the effects of lockdowns, restrictions on movement, limited access to food and medicine, and underfunded health systems remain a reality for many people, especially the most economically and socially vulnerable.

Two years into the COVID-19 pandemic, many community-based organizations, including their staff and clients, have experienced multiple waves of the pandemic while also experiencing some of the world's lowest vaccination rates. Based on this inequitable access to vaccines, the Africa Centre for Disease Control and Prevention aims to vaccinate 60% of the African continent by the end of 2022,[14] which is more than a year-and-a-half after similar targets were reached in many other parts of the world.

In addition to the illness and death caused by COVID-19, the pandemic has caused disruptions in people's access to HIV treatment, and to prevention commodities such as condoms and lubricants. It has reduced HIV testing, delayed HIV treatment initiation (including to prevent the transmission of

13. United Nations, "**Addressing inequalities and getting back on track to end AIDS by 2030: Report of the Secretary-General**" (New York, 2021), 15.
14. SABC, "**The goal is to vaccinate 60% of Africans by 2022: Africa CDC**" SABC News (Johannesburg, South Africa) January 15, 2021.

Kitovu Mobile, Uganda, Photo provided by Kitovu Mobile

HIV between a mother and child in utero, during birth, or while breastfeeding), and interrupted the uptake and consistent use of PrEP (pre-exposure prophylaxis). Isolation created by lockdowns has led to increases in gender-based violence and discrimination against LGBTIQ communities and sex workers. Together these effects of the COVID-19 pandemic are threatening to undo decades of progress made in the response to HIV and AIDS.[15]

Despite these troubling impacts, preliminary reports suggest that HIV testing and treatment numbers rebounded in mid-2020 in many sub-Saharan African countries after the initial damaging effects of COVID-19 restrictions.[16] This was due in large part to the efforts of community-based organizations that swiftly pivoted and adapted to their new realities, working closely with governments to maintain HIV services and social supports.

When people avoided health facilities out of fear of contracting COVID-19, and others couldn't reach them due to lockdowns and lack of transportation, an increased number of HIV and AIDS clinical services needed to move to communities. This included testing, ART refills, and viral load monitoring. As

15. For a fuller understanding of the impact of the COVID-19 pandemic on HIV and AIDS programs and on communities affected by HIV, see, for example, UNAIDS, "**The Effects of the COVID-19 Pandemic on the HIV Response**" (Geneva, 2021) and UNAIDS, "**Global AIDS Update: Confronting Inequalities – Lessons for Pandemic Responses from 40 Years of AIDS**" (Geneva, 2021), 206-220.
16. UNAIDS, "**Global AIDS Update: Confronting Inequalities – Lessons for Pandemic Responses from 40 Years of AIDS**" (Geneva, 2021), 208-209.

a result, throughout the height of the COVID-19 pandemic, community-based organizations delivered health services directly to communities and households. In addition, CBOs mobilized emergency food support for community members who lost their livelihoods, distributed masks and other PPE to people at the greatest risk of contracting COVID, and provided a myriad of wrap-around services to address people's physical and mental health.

Importantly, community-based organizations leverage their relationships of trust with their community members to share the benefits of COVID-19 vaccination and challenge myths that cause vaccine hesitancy. Home-based care programs are collaborating with local health facilities to host or amplify vaccination clinics and provide free transportation to vaccination appointments for other members of the community.

The innovation embodied by community-based organizations during the COVID-19 pandemic has always underpinned their work. Entrenched barriers to accessing health care were exacerbated by this new pandemic, and it became impossible to deny the role of community-based care in the COVID-19 response. In addition to offering health care in communities and households, CBOs brought a deep understanding of communities' needs and the adaptability required to meet them.

Young Women Campaign Against AIDS (YWCAA), Kenya, Photo provided by Young Women Campaign Against AIDS


PROVIDING ROUTINE VACCINATIONS
EDUCATING ON HEALTH
DELIVERING NUTRITIOUS FOOD
MONITORING ARV ADHERENCE AND WELLNESS
POST PARTUM SUPPORT
HBC worker
BATHING CLIENTS AND DELIVERING MEDICINE

The response of community-based organizations to COVID-19 offers an even deeper look into the value of a community-based health model by broadening our understanding of what 'good health' means and what meaningful access to health systems can look like. In a period of great unknowns, CBOs have stepped up yet again to fortify national responses to health crises, through their responsiveness and close connections to their communities. HBC workers put themselves at great risk to ensure that no one is left behind and that the inroads made in the HIV and AIDS response are not completely eclipsed by COVID.

As community-based organizations move from short and medium-term COVID-19 response and recovery to building long-term resilience, the intensified demands on these organizations needs to be matched with effective support, meaningful acknowledgement of their expertise, and sustainable, flexible core funding.

This support will be critical for CBOs to respond to evolving needs, and to provide an integrated response to HIV and AIDS that encompasses digital solutions, mental health, gender equality, support for community health workers, and enhanced multi-sectoral collaboration. By strengthening community-based care systems, grassroots organizations across sub-Saharan Africa can address the ongoing effects of the HIV and AIDS and COVID-19 pandemics while safeguarding against future pandemics.

"By strengthening community-based care systems, grassroots organizations across sub-Saharan Africa can address the ongoing effects of the HIV and AIDS and COVID-19 pandemics while safeguarding against future pandemics."

mothers2mothers (m2m), Lesotho, Photo by Ryan Tantuan

AN ONGOING AND URGENT NEED

Even before the far-reaching impact of the COVID-19 pandemic, it was clear that UNAIDS' 90-90-90 targets[17] would not be met as intended in 2020. By the end of 2019, the global community was 5.4 million people short of meeting the goals for treatment initiation and adherence.[18] Despite the ongoing and significant need to reach more people with HIV services, overall international HIV assistance declined by nearly 10% from 2015 to 2019.[19] This underinvestment, according to the United Nations, is partially responsible for the failure to reach the 90-90-90 targets.[20]

As the global community moves to the new targets of 95-95-95 by 2025,[21] it is essential to strengthen the strategies that can target the hardest-to-reach communities. Home and community-based care 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. In 2021, almost three-quarters of the SLF's partners who provide home-based care reported treatment adherence rates at or above 90% and two-thirds of those were at 95% or higher.

Compounding the underfunding of the HIV response is the reality that where HIV and AIDS funding does exist, it rarely goes into the hands of community-based organizations and into home and community-based care. When funding does make it to community-based organizations, it is too often constrained in ways that limit its effectiveness. To have the greatest impact in increasing the reach of HIV services and supporting the overall health and well-being of communities, community-based organizations need support that is sustained, flexible, and responsive to communities' needs.

17. This refers to 90% of all people living with HIV knowing their HIV status, 90% of all people with diagnosed HIV infection receiving sustained antiretroviral therapy and 90% of all people receiving antiretroviral therapy having viral suppression. UNAIDS, "**90-90-90 An ambitious treatment target to help end the AIDS epidemic**" (Geneva, 2014).
18. UNAIDS, "**Global AIDS Update: Seizing the Moment—Tacking Entrenched Inequalities to End Epidemics**" (Geneva, 2020), 13.
19. UNAIDS, "**End Inequalities. End AIDS. Global AIDS Strategy 2021-2026**" (Geneva, 2021), 49.
20. United Nations, "**Addressing inequalities and getting back on track to end AIDS by 2030: Report of the Secretary-General**" (New York, 2021), 22.
21. In addition to addressing testing, treatment, and viral suppression, the 2025 goals specifically target inequalities. To learn more, see UNAIDS, "**Ambitious Targets and Commitments for 2025**," (Geneva, 2021).

"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 [COVID-19] pandemic will have long-term impacts and cannot be solved by pre-2020 contribution amounts."

– Center for Disaster Philanthropy & CANDID[22]

The UNAIDS 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" and prioritizes "maintain[ing] and increas[ing] donor funding, including for addressing the root causes of inequalities through community-led responses."[23]

In a recent UN report, the Secretary General emphasizes:

"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 programmes; and expanded the reach, scale and quality of health services."[24]

The ongoing global COVID-19 pandemic has further negatively 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. Now, more than ever, when our very ability to physically connect with those around us has been greatly limited, it is important to strengthen the structures that ground us in our shared humanity. Community-based organizations have the ability to do just that. They offer the support and reassurances needed to combat the isolation, marginalization, and discrimination that result from continued systemic global health inequalities.

In order to respond to the HIV and AIDS pandemic, we must resource proven interventions, close service gaps, and reach the populations in greatest need. 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 the will and action of national governments and funders at all levels

22. Candid and Center for Disaster Philanthropy, "**Philanthropy and COVID-19: Measuring One Year of Giving**" (2021), 26.
23. UNAIDS, "**End Inequalities. End AIDS. Global AIDS Strategy 2021-2026**" (Geneva, 2021), 51.
24. United Nations, "**Addressing inequalities and getting back on track to end AIDS by 2030: Report of the Secretary-General**" (New York, 2021), 22.

to demonstrate leadership in this key area of global health and development by increasing current levels of support for community-based organizations and making significant new investments for home-based care. Community-based organizations that are run for and by community members feel the effects of national and global crises most acutely, yet with limited economic resources, they continue to invest in the people around them who need it most. This is the legacy of the community-driven response to HIV and reflects the depth of their will, skill, and experiences. They do not do this alone but work collaboratively with national governments, networks, and international development actors as an integral (even while undervalued) part of the health system tapestry. They deserve recognition, respect, and resources that match their clearly demonstrated value.

mothers2mothers (m2m), Lesotho, Photo provided by mother2mothers

"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."[25] *– UNAIDS*

Swaziland Nurses Association, Eswatini, Photo by Claudia Ramos

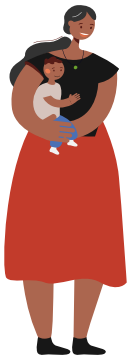
25. UNAIDS, **End Inequalities. End AIDS. Global AIDS Strategy 2021-2026**, (2021), p. 59-60.

67% of people living with HIV are in sub-Saharan Africa

In **13/15** countries where the SLF works, there are fewer than 3 doctors for every 10,000 people

Only **3%** of global health workforce is in this region

International HIV assistance declined by nearly



10%

between 2015 and 2019

70%

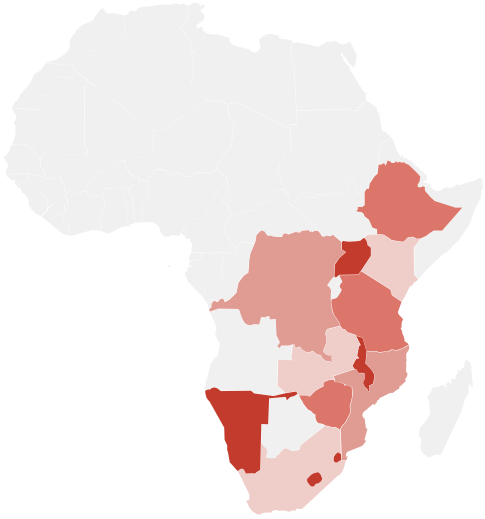
SLF's partners work with more than 5,000 HBCs; 70% of them are female

40 of the SLF's partner organizations reach more than

50,000

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

THANK YOU TO THESE ORGANIZATIONS FOR THEIR CONTRIBUTIONS



DEMOCRATIC REPUBLIC OF THE CONGO

- HEAL Africa
- Panzi Hospital

ESWATINI

- Swaziland Positive Living
- Swaziland Nurses Association

ETHIOPIA

- Action for Bright Future Association
- Negem Lela Ken New HIV Positive Women Support Organization

KENYA

- Kiambu People Living with HIV/AIDS
- Living Positive Kenya
- WEM Integrated Health Services
- Women Fighting AIDS in Kenya

LESOTHO

- mothers2mothers

MALAWI

- Centre for Alternatives for Victimised Women and Children
- Ekwendeni Hospital HIV/AIDS Programme

MOZAMBIQUE

- Kukumbi – Organization for Rural Development
- Mozambican Treatment Access Movement

NAMIBIA

- Catholic AIDS Action
- Tate Kalunga Mweneka Omukithi wo “AIDS” Moshilongo Shetu

SOUTH AFRICA

- Amandawe Community Care and Youth Development Centre
- Cotlands
- Ekupholeni Mental Health Centre
- Hillcrest AIDS Centre Trust
- Keiskamma Trust
- Siyanqoba Community Support Group
- Tateni Home Care Nursing Services
- Umdoni and Vulamehlo HIV/AIDS Association
- Wide Horizon Hospice

TANZANIA

- Catholic Diocese of Moshi, Rainbow Centre
- Kimara Peer Educators & Health Promoters Trust Fund
- Maasai Women Development Organization
- Pastoral Activities and Services for People with AIDS
- Umoja Wa Mapambano Dhidi Ya Ukimwi

UGANDA

- Action for Community Development
- Action for Rural Women’s Empowerment
- Kitovu Mobile
- Kyetume Community Based Health Care Programme
- Nyaka AIDS Orphans Project
- Nyimbwa Multi-Purpose Organization of People Living with HIV/AIDS
- Reach One Touch One Ministries
- Reach Out Mbuya Community Health Initiative
- St. Francis Health Care Services

ZAMBIA

- Community Based Care Foundation
- St. Marks Widows Group
- Twavwane Home Based Care Initiative
- Ranchhod Community Services and Hospice

ZIMBABWE

- Hope Tariro Trust

Catholic AIDS Action, Namibia, Photo by Alexis MacDonald