

Community-Based Organizations:

*Reaching HIV-positive
Children & Youth in
sub-Saharan Africa*

Photographer: Alexis MacDonald/SLF



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Treatment Action Campaign | Photographer: Alexis MacDonald/SLF

Community-Based Approaches

Closing the child & adolescent treatment gap

HIV & AIDS CONTINUES TO WREAK HAVOC on the families and communities of sub-Saharan Africa, and the epidemic has had an especially devastating impact on children and youth. In 2016 there are a staggering 14 million children who have been orphaned by AIDS, and close to three million children living with AIDS. Only one in three HIV-positive children currently has access to treatment. Rates of treatment default and new infections among adolescents are alarming, and 7 in 10 new infections for teenagers in sub-Saharan Africa are among girls.

One of the biggest challenges is that a whole generation of parents has died and community structures have been badly compromised. In so many cases it has been the grandparents — predominantly elderly, widowed women — who have stepped into care for the orphaned children. But the grandmothers

themselves have been traumatized by loss, and are sorely lacking the physical, emotional and material resources they need to care for this multitude of children. These families struggle with poverty, making malnutrition a constant threat. HIV-positive children are often ostracized and discriminated against,

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with little protection from abuse. Education is terminated and children's hopes of living productive, self-supporting lives are dimmed. Gender-based discrimination greatly increases girls' vulnerability to sexual exploitation and

violence, as well as their risk of HIV infection. And children struggle with all of the grief and loss they have endured, and continue to suffer.

The response that community-based organizations are rolling out – through a multitude of varied interventions – is driven by a single, essential insight. Children infected and affected by HIV & AIDS must be supported as whole persons. The community-based organizations that are succeeding in reclaiming these children's lives have learned that HIV treatment must be delivered as a part of much more encompassing, holistic programmes of support, which address the children's multiple vulnerabilities. The provision of a range of wrap-around services to accompany ARV treatment is absolutely necessary. Children's nutritional and other material needs must be met, and they need to learn life skills and receive counselling, including play and art therapy. Caregivers need training to administer medication, and also parenting skills, education on nutrition, support to deal with their own grief,

and means to obtain basic incomes for their families. Age appropriate interventions are needed for youth, especially in relation to their sexual and reproductive health and rights. Community bonds need to be strengthened, and youth groups and caregivers' groups play crucial roles in encouraging testing and adherence to treatment. HIV & AIDS education and

Family and community connectedness are key to building resilience in HIV affected and infected children and youth.

awareness raising must be grounded in ongoing education, and the self-confidence that comes from learning. Family and community connectedness are key to building resilience in HIV affected and infected children and youth. Community-based organizations have found that the orphaned children who succeed, and the HIV-positive children whose treatment is maintained into adulthood, are those who have come to see themselves as part of the solution, are in school, have access to counselling, are active members of functioning families and communities, and have a sense of agency about their futures.

The 2016 International AIDS Conference in Durban, South Africa, comes at a crucial moment in the evolution of global, national, and local responses to the HIV & AIDS epidemic. The urgency of improving treatment adherence rates for children and youth could not be clearer. Equal clarity is now needed about the approaches and interventions that really do work to support children and youth infected and affected by HIV & AIDS, so that greater funding can be secured, and lessons can be learned and replicated much more broadly. Five long-time partners of the Stephen Lewis Foundation, based in Uganda and South Africa – **Reach Out Mbuya Parish HIV/AIDS Initiative**, **MUJHU Care**, **St. Francis Health Services**, **Cotlands**, and the **Blue Roof Wellness Centre** – are sharing their invaluable expertise, insights and programming experience at the Conference's Global Village. Their many, important innovations include:

- Specialized HIV clinics, staffed by pediatricians and counsellors with expertise in psychological support for young people, which use child friendly environments and play therapy to help identify the children's health and well-being issues.
- Home-based adherence counselling and monitoring provided by teenage peer counsellors, who are living with HIV themselves, and are supported by and closely linked with comprehensive HIV clinics.
- Targeted capacity building for community health workers and home-based care workers, so that they can confidently engage with and counsel children, and support the children's caregivers to deal with disclosure and maintaining treatment.
- Vigorous, pro-active outreach to families, community groups and other local organizations, to help identify HIV-positive children who have not yet been tested, and bring them into care.
- Integration of HIV care and monitoring into childhood early learning initiatives, to help access those families who are uneasy about attending clinics and medical facilities because of possible HIV-related stigma and discrimination.
- Programming for orphaned children's grandmothers – including psycho-social care, medical care, parenting and adherence training, and income generating activities – to help the grandmothers regain their resilience and overcome the multiple challenges to support their families.
- Mutual support groups for HIV-positive young people, where they find safety and a sense of community with their peers, free from fear and stigma, learn to cope with the difficult task of living positively in their teenage years, and develop the self-esteem they need to take on leadership roles.
- Ongoing support to keep children in school, to prevent the early termination of their education, and the increased risk of treatment adherence default and HIV infection that too often follows. Education support must include dedicated attention to early learning to maximize children's opportunities to succeed.

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WHAT IS MOST IMPORTANT TO RECOGNIZE, APPRECIATE and support is the holistic nature of the programmes that community-based organizations are implementing. These initiatives are not stand-alone measures, they're not 'quick fixes,' and none of them have been undertaken in isolation. Community-based organizations understand that infection with the virus is, sadly, only one of the many blows these children have had to absorb and from which they will have to recover in their young lives. Their programming is realistic – and effective – because it aims to support the whole child.



Reach Out Mbuya Parish HIV/AIDS Initiative, Uganda

Reaching children through their families and communities

THE REACH OUT MBUYA PARISH HIV/AIDS INITIATIVE is a community-based organization that has been working with the urban and rural poor communities of Uganda's Kampala, Wakiso, Kasaala and Luwero districts for 15 years. ROM has supported its clients through a holistic, comprehensive, community-based model – involving free medical, social, emotional and spiritual support – delivered through four clinics, mobile outreach services, and an extensive volunteer base of community health workers. Currently ROM is serving over 8,000 HIV infected individuals, 90% of whom are on anti-retroviral therapy, over 8,000 orphaned and vulnerable children, and over 1,200 grandmothers.

The daunting challenge of maintaining ARV adherence for children and adolescents has been a special programming focus for the organization. ROM has been providing children and adolescents with testing, treatment and clinical services for many years, and now a new monthly pediatric/adolescent

Complementing the clinical work, ROM embraces children within a community network of care.

clinic has also been established, staffed by a pediatrician and counsellors trained in psycho-social support for young people. A child friendly environment is fostered during clinical care, with play therapy that helps children open up and assists ROM staff to identify issues that need to be addressed. Sessions on sexual and reproductive health are also conducted during the clinic for adolescent clients.

At the same time, complementing the clinical work, ROM embraces young people within a community network of care. Their 'Teenage and Adolescent Supporters' are peer counsellors – mostly young people living with HIV who are also ROM clinic clients – selected from the villages in which they will be serving, and trained in the basics of HIV adherence and follow-up. They make over 6,000 regular home visits to all of ROM's young clients every year, checking on the children's well-being, counting their pills, keeping in close contact with the clinic about any health concerns, family or social problems that arise, and making sure the children attend their appointments. ROM also runs a 'Friends Forum' for their young clients, where they can talk with one another about their experiences and challenges, a music, dance and drama group, and an annual camp for children and teenagers living with HIV.

So many of these children have been orphaned by AIDS, and are in the care of their grandmothers – often elderly, widowed women with little or no source of income, and serious health challenges of their own. Since 2014, ROM has been working with grandmothers in the Kasaala and Luwero districts, to improve their well-

being and their capacity to support their grandchildren. The grandmothers are receiving medical assistance through weekly grandmothers' clinics, mobile outreach services and home-based care visits, and they are joined together in support groups for income

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generating activities and village savings and loans associations. ROM also provides training and individual counselling on the care, support and treatment of children living with HIV & AIDS, focusing on critical issues such as disclosure, adherence, stigma and discrimination, and prevention.

ROM's work to improve child and teen ARV adherence is premised on the understanding that strong family and community connections are critical for children's health. ROM has learned through its years of programming experience that health service delivery must extend well beyond drug prescription and supply. The young girls and boys who succeed with ARV treatment into adulthood have been supported as whole persons, and they've been given the chance to be children.



MUJHU Care, Uganda

‘Young Generation Alive’

MUJHU CARE LIMITED IS A UGANDAN not-for profit established in 2005, in association with the Makerere University-Johns Hopkins University Research Collaboration. The two universities’ research collaboration had a primary focus on reducing mother to child transmission of HIV, and MUJHU Care was created to continue and extend this mission to improve the health status of families infected and affected by HIV & AIDS.

MUJHU saw that children and adolescents who had been on treatment for a long time, many positive since birth and on ARVs for many years, were starting to falter. This was often due to poor adherence associated with pill burden and other factors. MUJHU engaged a multi-disciplinary team of doctors, counsellors and social workers who have gone the extra mile to emphasize the importance of

adherence, the danger of resistance, and to support children to take their medications consistently. MUJHU also recognized early on that young people have very different psycho-social needs from their parents. HIV-positive children and adolescents

were reporting real difficulty in dealing with the stigma and discrimination they were being subjected to at school, and in their own homes. Many of the children had become depressed, had low self-esteem, had dropped out of school or were performing very poorly, and their adherence to medication was not good. MUJHU responded with its 'Young Generation Alive' programme, designed to address these unique psycho-social challenges.

A central pillar of the programme is the monthly psycho-social support group meetings that MUJHU facilitates. Over the past five years, more than 4,500 children have participated in the meetings, and many have found them life-changing. The Young Generation Alive (YGA) group has enabled many children and adolescents with HIV to overcome internalized stigma and build self-esteem, and MUJHU has tracked a measurable increase in self-esteem for more than 100 YGA members, using the Rosenberg Scale, from 20% in 2006 to 60% in 2010. The change is also evident in their readiness to talk about and accept their HIV status, the openness and leadership they demonstrate in support group discussions, their participation as speakers in public meetings and conferences about HIV care and treatment, and their advocacy for voiceless HIV-infected children in rural areas. The group is also an important vehicle for HIV education, and age appropriate education about sexuality and reproductive health.

MUJHU is supporting and training the peer adolescent leaders who have emerged from the Young Generation Alive group, and these young leaders are assisting MUJHU in efforts to address stigma and discrimination through school and community outreach. MUJHU sensitizes approximately fifty schools a year with information about HIV transmission, prevention, management and stigma, and consults with school nurses about individual children's treatment. They also conduct community sensitization events, including at places of worship, to reduce discrimination and help change the very damaging misperception that investing in the education and development of children living with HIV is not worthwhile.

YGA has empowered its child and teenage members with new understandings, self-esteem and skills, and they are highly motivated to become part of the solution.

Young Generation Alive has empowered its child and teenage members with new understanding, self-esteem and skills, and they are highly motivated to identify problems and become part of the solution. YGA has facilitated a shift in young peoples' mind sets, from dependence to self-reliance. Not

only has there been a reduction in school drop outs and pregnancies, but the YGA members and peer leaders are hard at work within their communities, supporting others to adhere to treatment and reduce risky behaviors, and advocating for the rights of children and adolescents living with HIV.



St. Francis Healthcare Services, Uganda

Grandmothers & the children in their care

ST. FRANCIS HEALTH CARE SERVICES IS a community-based organization that has been working in the field of HIV & AIDS prevention and care since 1998, in the Mukono, Buikwe and Soroti districts of Uganda. Starting out as a fledgling organization with 89 clients, St Francis has grown to serve a clientele of over 10,000, and it has been the largest ARV provider in Buikewe district for the past five years. St. Francis offers a holistic approach, designed to cater for the needs of people living with HIV & AIDS, orphans and vulnerable children, youth, and grandmothers, complementing its comprehensive HIV medical services with home-based care and psycho-social assistance.

Strengthening families is a crucial intervention for addressing the challenges that come with the HIV & AIDS epidemic.

mothers have been instrumental for many years in mitigating, curbing and containing the damage inflicted on children who have been orphaned by AIDS, but without any substantial support or recognition. They have been taking care of sick and vulnerable children without the healthcare skills, or capacity to handle the challenges of parenting at an older age that they need, and are severely stretched to provide for their grandchildren's basic necessities. Many lack the strength, and resources, to make the long journeys to access quality medical support for themselves and their grandchildren. The programmes run by St. Francis have been restoring hope and dignity to these families, empowering grandmothers, and helping to ensure brighter futures for their grandchildren.

Support for grandmothers takes the form of income generating activities, agricultural activities, microfinance and savings groups, psycho-social support and advocacy forums. Training and counselling is provided on child treatment adherence, parenting skills, child protection issues, nutrition, and backyard gardening, and legal guidance is

provided on issues such as will making and protection from land grabbing. Each Friday the St. Francis medical center dedicates its time to treating grandmothers and HIV positive children, and home-based care visits ensure monthly medical check-ups for all family members. Inability to pay for school fees is one of the grandmothers' biggest worries, and the programme provides some educational support for the grandchildren. As well, the 'Shadow Idol Club' operates every Saturday, bringing school-age children together for recreational and educational activities, psycho-social support, mentorship, and information sharing about HIV prevention, treatment adherence, and sexual and reproductive health. The children share testimonies with each other, and engage in music, dance and drama.

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St. Francis Healthcare Services | Photographer: Jane Farrow/SLF



Cotlands, South Africa

Early learning opens doors

COTLANDS WAS FOUNDED IN 1936 AS A SANCTUARY for orphaned children and, while the organization has undergone many changes over the years, it has always retained the primary goal of caring for young children. Beginning in 1999, Cotlands has delivered comprehensive, community based programming on HIV and nutrition, complemented by psycho-social and educational support, to six South African provinces: Gauteng, KwaZulu-Natal, Eastern Cape, Western Cape, Mpumalanga, and North West. Cotlands' early learning programme was introduced in 2013, and has become an important means of identifying and supporting HIV-positive children.

Cotlands realized that early childhood education is essential to enable communities to break out of the poverty cycle that is associated with a high incidence of HIV & AIDS. Young children living in disadvantaged, AIDS-affected communities have limited or no access to early learning opportunities. When these children start school they are

usually behind in their educational development, and HIV-positive children also have to contend with the additional burden of poor health. The lack of fundamental skills needed to learn to read and write impacts negatively on their whole learning experience. Often it's not possible to close the developmental gap, and many children are forced to repeat classes, can't achieve their academic potential and end up leaving school prematurely. Without adequate education their employment opportunities are limited, they struggle to earn an income and find a place in life, and their chances of defaulting on treatment or becoming infected with HIV increase.

In KwaZulu Natal, Cotlands' nurses, social workers and early learning facilitators deliver a carefully coordinated array of services to ensure children's protection, survival and psycho-social development. There are two early learning programmes, a playgroup for infants and children up to two years old, and a playgroup for two to four year olds. The first playgroup focuses on opportunities for parents and caregivers to bond with their children, stimulate their minds and imaginations, and learn how to meet the children's physical, emotional and nutritional needs. The playgroup for children ages 2 to 4 offers creative learning and play opportunities that help develop language skills, mathematical problem solving, motor skills, and social and emotional abilities.

Nurses and social workers visit the early learning playgroups at least once a month. The nurse assesses the children's general health, screens children for symptoms of HIV, TB and other illnesses, measures and weighs the children to check for stunted growth and poor nutrition, and checks immunization cards. Any child identified with a potential health problem receives a follow-up visit from the nurse, who will decide if she should treat or refer the child. She also gives the family guidance on preventing and managing HIV and other illnesses, as well as supporting families in adhering to treatment and the prevention of mother-to-child transmission. The social workers identify orphans and vulnerable children, provide psycho-social counselling, and assist families to access government services. One of the benefits Cotlands has seen from its early learning programme is that families

Cotlands has seen that many families become more open to receiving HIV-related services when the entry point is preschool education.

become more open to receiving HIV-related services when the entry point is preschool education. For many, this can be a less threatening, more accessible way to begin addressing HIV, malnutrition and psycho-social concerns.



Blue Roof Wellness Centre, South Africa

Modelling comprehensive care

THE BLUE ROOF WELLNESS CENTRE, LOCATED in the Wentworth community of Durban, was founded in 2005. They are currently providing HIV services to over 2,300 adolescents, children and adults living with HIV through a best practice model site providing holistic health services and innovations, training, and research to radically minimize the impact of HIV for children and adolescents in Durban and beyond. Blue Roof's services include HIV counselling, testing, care and anti-retroviral therapy, psycho-social and adherence support, nutritional support, tuberculosis and cervical cancer screening, and linkages to substance abuse counselling. Blue Roof works to ensure that people living with HIV have access to comprehensive, dignified care and treatment, incorporating the critical 'wrap-around' services that are so important for enhancing long-term retention in care and adherence to treatment.

Active community outreach is essential, and parents and caregivers need to be engaged, prepared, and counseled to bring their children in for testing.

In partnership with Zoë-Life, Blue Roof is expanding and deepening its provision of HIV services for children and youth in the Durban South basin area. A broad range of services and activities for children and youth are being offered, and key drivers of HIV such as economic and social vulnerability are also being addressed. One of the priorities is identifying and offering testing and counselling to as many undiagnosed children and youth as possible. Children do not voluntarily arrive for testing — active community outreach is essential, and parents and caregivers need to be engaged, prepared and counselled to support them to bring their children in for testing. Blue Roof is using a family screening tool to identify children who have not yet been tested, and is also reaching out to early childhood development centers, community-based HIV support groups, children's residential homes and organizations that provide services to children who have been sexually assaulted. Adolescents are often not comfortable attending clinics, and the strategy with them is to open the door through Blue Roof's art, dance, exercise, music, career, and entrepreneurship support services. All of these activities incorporate youth-friendly discussions and debates, counselling about HIV, sexual and reproductive health, and family planning, as well as linkage to clinical services.

A corner-stone of the work is Zoë-Life's 'Kidz Alive' programme, which is being expanded nationally by the South African Department of Health, and for which Blue Roof will serve as a model and training centre. Kidz Alive helps build capacity for healthcare workers and community workers to engage with children around health

issues, especially HIV counselling and testing. Healthcare workers and community workers often feel intimidated when asked to counsel a child, and feel uncertain about how to relate to children. Kidz Alive builds confidence, and skills to work with, engage, and counsel children in their own language, using play and art techniques, and provides ideas for creating child-friendly space in which children will feel safe and comfortable while dealing with sensitive issues. Training is also provided for counsellors and facilitators of HIV support groups, so that they can be better prepared to guide children's caregivers on issues of disclosure and adherence. The focus is on supporting caregivers to resolve their own barriers to self-acceptance, and creating environments and relationships of trust. When the caregivers' own resilience increases, they become more willing and able to bring their children in for HIV testing, and have disclosure discussions with them.

Blue Roof helps healthcare workers learn to engage and counsel children in their own language, using play and art techniques.

Keep a Child Alive (KCA) is one of Blue Roof's founding partners along with the Stephen Lewis Foundation. KCA is a 501 (c) (3) nonprofit that works to realize the end of AIDS for children, youth, and families. Leigh Blake and Alicia Keys – luminary activists in the entertainment industry – founded KCA in 2003 to respond to the urgent and unmet need for HIV treatment in sub-Saharan Africa. Building on their vision, KCA's approach has grown from grant-making to partnering with grassroots organizations to design, implement, and share innovative solutions to some of the most pressing problems in the fight against AIDS – reaching over 70,000 people annually. Today, with seven programmes in five high HIV-burden countries (India, Kenya, Rwanda, South Africa, and Uganda), KCA aims to: reduce the vulnerability of women and girls; eliminate the HIV prevention and treatment gap for children; and address the spiraling epidemic of HIV among youth. They bring creativity to global health, including integrating music and the arts into HIV care and healing. Together with their partners, they work at the frontlines of the epidemic to engage those on the margins, blending local solutions with global knowledge and capacity building for transformative impact.

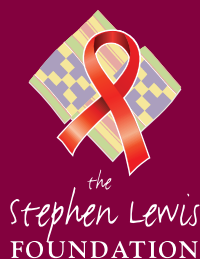
The Stephen Lewis Foundation

Partnerships at the heart of child & youth care

THE STEPHEN LEWIS FOUNDATION HAS been partnering with grassroots community-based organizations to turn the tide of the HIV & AIDS epidemic in sub-Saharan Africa since 2003. At a time when Africa was reeling from one of the greatest health emergencies in human history, people in the communities most affected by AIDS had rallied themselves to confront the crisis that was devastating their lives, and their small, emergent organizations were struggling to put their plans into action. In 2003 we were convinced that if only funding could be transmitted directly to these community-based organizations, some of the forward movement that was so urgently needed could begin.

As of 2016, the Foundation has disbursed \$90 million, working in partnership with over 300 community-based organizations on more than 1,400 initiatives in the 15 sub-Saharan African countries hardest hit by the epidemic: Botswana, the Democratic Republic of Congo, Ethiopia, Kenya, Lesotho, Malawi, Mozambique, Namibia, Rwanda, South Africa, Swaziland, Tanzania, Uganda, Zambia, and Zimbabwe.

These community-based organizations were most frequently born out of the resolve of small groups of individuals, who, after witnessing the devastation of HIV & AIDS in their personal lives, began to work determinedly to save their communities. Over the years they have grown and evolved to become important and trusted local institutions, and leaders in the fight against AIDS.



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