

ELTON JOHN AIDS FOUNDATION

EJAF FUNDS SUPPORT CREATIVE AIDS PROJECTS

“HIV-related stigma and discrimination remain an immense barrier to effectively fighting the most devastating epidemic humanity has ever known. HIV thrives on intolerance and xenophobia. It is always easier to blame others for the spread of HIV but progress against the epidemic is only possible when communities own the problem of AIDS themselves.” --
UNAIDS Executive Director Peter Piot, World Conference Against Racism, Sept. 5, 2001

Two recent Elton John AIDS Foundation (EJAF) projects offer an answer to the question, “How do we combat the stigma of AIDS?”

Stigma wanes, they tell us, when community groups address it forcefully. The evidence: two programs that – as they operate an ocean apart in Kenya and Brazil – are effectively challenging long odds to improve the lives of

people with HIV and AIDS.

Modest Means, Model Results

The projects include a training program developed by KICOSHEP, the AIDS self-help services group in Kibera, Kenya’s biggest slum, and Brazilian work on an anti-stigma campaign in São Jose do Rio Preto, a city on the outer perimeter of São Paulo state.

Both projects were inspired by one idea – to attack stigma head on, using the well-tested



Kibera (Nairobi, Kenya) - in 1993

principle that to create new attitudes toward AIDS, you must target broad audiences, “opinion leaders” or both. Project leaders in São Jose chose to promote their anti-stigma message widely, deploying a range of media and materials. Meanwhile, Nairobi’s KICOSHEP initiative focused on church and community leaders. Both delivered results with modest means.

According to the groups’ veteran leaders, the frontal attack on stigma was unavoidable. Prejudice remains the single largest obstacle to HIV/AIDS prevention and care in many parts of the world. It can obliterate even the results of strong, well-funded programs, says Maria Eugenia Fernandes of Associação Saúde da

Família (ASF), who has been project head for a number of AIDS programs in Brazil.

These projects pose lessons to anyone willing to learn from their example. Below we analyze the work of these AIDS service organizations, and review how they generated model outcomes with modest means.

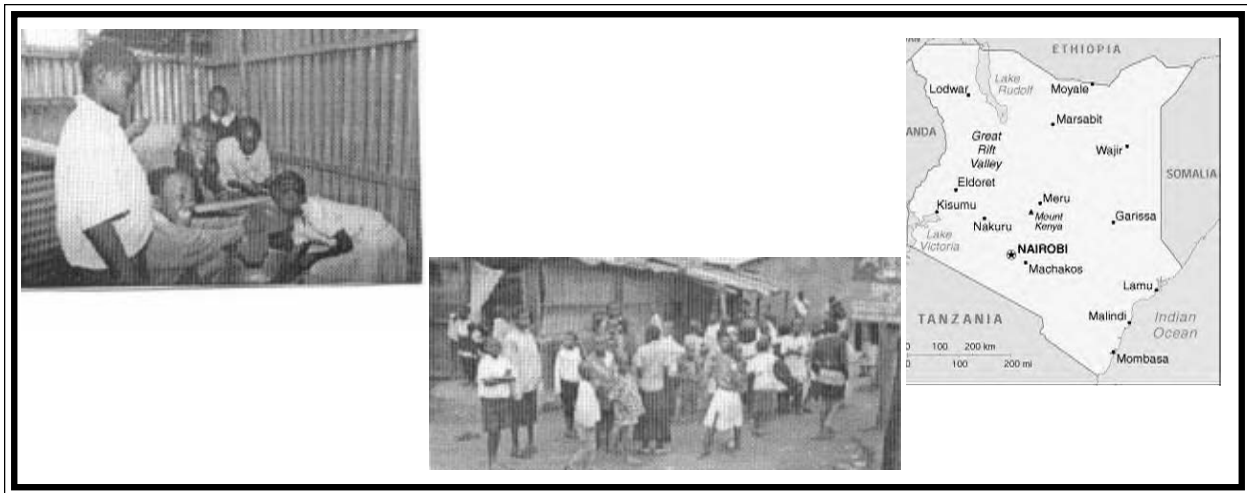
The Rapid Response Fund (RRF) was born in 1999 when the Elton John AIDS Foundation (EJAF) and Family Health International (FHI) began collaborating on HIV/AIDS programs.

The Fund channels FHI’s expertise and global presence and bolsters it with the resources of EJAF, which supports thousands living with HIV in the United Kingdom, United States and throughout the world.

RRF grants are limited to £3,000 (approximately \$5,000), and target local NGOs and community based groups working with HIV/AIDS prevention and care. Supported programs include:

- Educating the public
- Intervening with high-risk groups
- Intervening with youth populations
- Providing care and support
- Caring for orphans and vulnerable children

EJAF and FHI selected eight countries for initial funding in 2000: Brazil, Cambodia, Honduras, India, Kenya, Nigeria, Russia, and Rwanda. Because the epidemic varies by culture and country, the program is designed to be culturally sensitive and adapt to the needs of the grantee groups. Thirty-six RRF grants and \$166,520 have been approved – and are now helping a broad range of organizations develop innovative projects.



Kibera - 2001: KICOSHEP offers services for orphans, children and adults

Kibera, Kenya: Getting “Opinion Leaders” to Model Genuine Attitude Change

“Don’t count on the authorities to help you in Kibera.” These grudging words are a reference to Nairobi’s biggest slum.

It is the message used by Kibera’s half-million residents, who make up a fifth of the population of Nairobi. It often was Kibera’s message to reporters covering Kenya’s presidential election in 1997. Kibera’s residents have long turned to groups like KICOSHEP, rather than government institutions, for support in their impoverished community.

But with new elections on the horizon, change is in the air. Kenya’s government is piggy-backing its AIDS programs onto the decade-long initiatives developed by KICOSHEP, Kibera’s self-help health education and health project targeting HIV/AIDS. And now churches are beginning to respond to the AIDS epidemic within Kibera too.

One reason for the change is a small training program launched this year by KICOSHEP Executive Director Anne Owiti, using Elton John AIDS Foundation (EJAF) funds in a creative way. KICOSHEP focused its training on key church and community leaders. It honed their skills in dealing with AIDS prejudice, the needs of volunteers, counseling, and home-based care.

Changes, as a result, are starting to cascade. As Mrs. Owiti puts it, “We have learned how to get church leaders to interact with us, to join our work on AIDS.” No sea change yet, but Mrs. Owiti sees a time when “we’ll have a very different picture of AIDS in Kibera.”

The key, for her, is the drop in public discrimination against people living with AIDS, particularly the 50,000 AIDS orphans and adolescents now in Kibera. The drop is palpable, she says, but “it will still demand a great deal of support and commitment in the future.”

For evidence, she points to an August 2001 Nairobi Times interview with the Catholic Bishop of Nairobi, who urged parents to talk frankly with their children about sex. “He tells us this,” Mrs. Owiti emphasizes, “and does not go back to preaching abstinence,” the Church’s normal stance when facing AIDS. And the 20 church leaders she trained in early 2001 are opening their churches for the first time to discuss HIV/AIDS and allow health screenings on church property.

Quiet yet unprecedented change is underway in Kibera. Peter Mwarogo, Deputy Country Director for FHI, agrees: “A big success for us in Kenya lately is having both the government and other institutions join the advocacy for HIV/AIDS.”

Needed: A Change in Attitudes

At first glance, Mrs. Owiti’s small scale RRF project seemed an unlikely candidate to bolster the extensive KICOSHEP programs already in Kibera. The project focus: to train 20 church and community leaders to become

So prior to drawing up workplans for individual churches, compiling volunteer lists, or discussing techniques for following up on AIDS counseling for church members, she began to address the attitudes of priests and ministers.

One Pentecostal minister initially complained that he did not want posters with pictures of condoms on church premises. Another seemed genuinely confused: Why all this talk of condoms when all they’re good for is family planning?

Forming New Alliances

By the end of the training, every church leader – for the first time publicly – committed himself to opening church doors to KICOSHEP. Even the minister complaining about condom posters agreed to display them prominently and now allows KICOSHEP to hold regular health screening clinics on church

During the KICOSHEP training, one local minister seemed genuinely confused: Why all this talk of condoms when all they’re good for is family planning? (He himself was proud of his large family, he insisted.)

more engaged in KICOSHEP’s health and prevention programs.

As training began at a community home in Kibera, Mrs. Owiti saw that because church leaders are “opinion leaders,” their first job was to change their own opinions on AIDS. And there were many candidates for attitude change.

property.

As Mrs. Owiti points out, “Property rentals are expensive for us. Any help we get by using church space is very important.”

“Kibera is one of Africa’s largest slums, and what they do there has value elsewhere,” reminds Dr. Eric van Praag, Director of HIV/

AIDS Technical Support Care at Family Health International. After a series of assessments of East African AIDS projects, he sees special skills at work in KICOSHEP programs.

Integrating Comprehensive Care and Prevention

Providing a variety of services is a key factor in creating strong AIDS programs, but it is exceedingly rare for all the needed services to be made available in one community and fully integrated. And yet Kibera has seen this happen.

“The real problem in developing countries is a lack of linkage among AIDS programs,” says FHI’s Dr. van Praag. He is referring to linkages across the board, in all phases of AIDS programs – from addressing the vulnerabilities of youth, to medical care, maternity facilities, social support, home care and orphan support.

This is critical, he points out, because a foundation of strongly linked programs, especially with prevention and care, allows the use of sophisticated tactics in battling AIDS. It may usher in follow-up programs for mothers with

AIDS, and allow treatment with antiretrovirals, for example.

“KICOSHEP tries to ensure it has a continuum of prevention and care, and links them,” adds Dr. van Praag. “This type of coordination,” he adds, “remains unique in Africa.”

Paving a Road to the Future

As for Mrs. Owiti, she knows she faces the need for “a great commitment to reach other opinion leaders.” It will be critical for KICOSHEP’s future success.

Equally high on her agenda is the ability to develop many services and train people to provide the services needed by very ill Kibera residents. She has only begun that process by using RRF funds to train both community and church leaders to respond to AIDS.

“But when we have the church on our side, we have a great deal,” she adds with a note of triumph in her voice.

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São Jose, Brazil: New Pin on the Map of Model AIDS Projects

Brazil, the regional “AIDS epicenter” in Latin America according to the United States Agency for International Development (USAID), offers other ready opportunities to fight AIDS discrimination.

Brazil’s own epicenter straddles the metropolitan regions of São Paulo and Rio de Janeiro. These two cities log two of every three HIV/AIDS infections in the country.

And after nearly a decade of fighting AIDS with local and global funds, “Brazilians see some hope,” says Maria Eugenia Fernandes. The national government fights hard to give 85,000 Brazilians with AIDS cutting edge medical treatment, and its reach is expanding

Brazil’s national strategy includes bolstering the institutions that provide HIV/AIDS programs and upgrading the ability to deliver services in high-poverty areas like Bahia, in Brazil’s Northeast.

But targeting prevention without addressing the stigma of AIDS “will defeat you over time,” Fernandes emphasizes.

This is where GADA, an AIDS service organization in São Jose do Rio Preto, enters our story. It’s the story of an organization with a long-term view and an effective approach to stigma.

Brazil remains the regional “AIDS epicenter” in Latin America and the Caribbean, according to the United States Agency for International Development (USAID)

– as is its ability to provide for a larger population, thanks to hard bargaining on price reductions with drug companies.

But the numbers for these major cities mask a picture that is more complex nationally. HIV is spreading through isolated parts of the country, says Fernandes. As a veteran of AIDS projects in major cities, she knows the problem well.

“In short, much remains to be done,” she emphasizes.

GADA’s Niche Role

Look for São Jose do Rio Preto on the map, and you will spot it as a speck quite a few hours’ drive from its celebrity neighbor São Paulo, capital of Brazil’s biggest state. If you check additional demographic maps, you’ll know that you are in crowded territory. São Paulo state, twice as populous as Brazil’s capital, is home to 35 million people.

São Jose, by comparison, is small – one percent of the area’s population – but it offers

hope to its 3,000 HIV-positive residents and families, mainly through the work of GADA (Grupo de Amparo ao Doente de Aids). Since its founding in 1993, GADA has served the most neglected of Brazil's AIDS-impacted groups, the children of AIDS affected families and the very low-income poor.

This “niche” focus yields results, even when measured against bigger AIDS programs of “paulistas” (São Paulo residents) elsewhere. (São Paulo, the world's second largest city, has far more resources than São Jose, of course).

What makes GADA's programs work is not simply the funding, nor its network of local support. “We're successful because we *are* local,” says project activity coordinator Mello Humberto. For him, the key to GADA's long-term success came from GADA's ability to “implement creative programs for children impacted by AIDS” -- and by leveraging local support from the city of São Jose do Rio Preto

and from GADA's network of supporters.

GADA vs. Stigma – A Behind the Scenes Look

For GADA, stigma is real, and a shadowy influence hampering its many programs for São Jose's children. Stigma, as a result, became GADA's target in its RRF project.

GADA's focus is a shelter serving children from AIDS-impacted homes. GADA's shelter houses children under 10 years old on week-days, gives them school uniforms, and uses a makeshift van to drive them to and from school. Despite long-term success with the children, charitable donations of food, clothing and other items have been inadequate.

With no funds for a van, GADA turned to creative tactics for a solution: It now uses a stolen 1988 Ford donated by the São Jose police to shuttle its children to schools.



One of GADA's 15 anti-stigma campaign billboards. Message: A child with AIDS is the same as one without AIDS. The single difference: Abandonment.

(Thieves filed off the vehicle identification number, so the owner is untraceable.)

Children respond to the GADA programs because they receive the care lacking in their own homes. Most of the 22 children come from abusive families with alcohol or drug-addicted (and HIV-positive) parents. GADA feeds and cares for them until the parents pick them up for home visits on weekends; on Mondays, they return to the shelter.

To bolster donations across the board, GADA focused on distributing anti-stigma materials to educate São Jose about children with HIV and AIDS.

This meant a broad “rollout” of the anti-stigma message, says Humberto, who also served as the project’s “idea man.” He speaks quietly, but with an expert’s pedigree: An author of four books, he also has lived with AIDS for more than a decade.

Humberto made sure that GADA placed billboards (see page 7) strategically on 15 of São Jose’s main roads. The big message was supplemented by similar anti-stigma messages on bumper stickers, newspaper inserts, 40,000 pamphlets and 250 public service radio announcements.

Broad Public Response

The results? “They were very gratifying,” says Humberto. Of all the responses, he says, “the billboards clearly had the biggest impact.” Callers to GADA’s office typically mentioned a billboard they had seen, then asked about ways they could help.

And help they did – GADA workers were gratified to see donors pay for telephone bills. This allowed GADA to devote more money to actual services.

The response to newspaper and radio ads drew attention – and donations – in still more ways. All told, the response to the anti-stigma campaign was heartwarming.

Humberto saw a surge in food and clothing donations pour in for the children’s shelter. “In the past, we had problems getting these, despite our good work, because of the stigma,” he added. Brazil’s AIDS-impacted children are a low priority in government AIDS programs, so EJAF funds go a long way, he says.

Equally important, GADA’s campaign worked against the grain of many Brazilian projects that try to address children’s services. “For whatever reason,” says Humberto, “whether it is corruption or other factors, even outside funds from big NGOs for children rarely are used *for* children. Children remain on the streets.” GADA’s services and the donations generated by the campaign, “went directly to the children of São Jose,” says Humberto.

What’s next for Humberto and his GADA colleagues? He offers a short list with two items. First, given the age of their 13-year-old school “shuttle,” a new car or van for driving children to school is a big priority.

Bigger still, but merely a vision for the moment, is a commitment by Rotary International, the US-based NGO, to provide \$50,000 to GADA – if GADA can match the funds.

This would be dedicated to equipping a building for the group's work. (The building itself is available, and was donated by the São Jose do Rio Preto municipal government.)

Raising these funds might be a tough task, he says, "but the outcomes of our project inspired us to try harder."

Closing Thoughts: Creating Broad, Sustainable Campaigns Against Stigma

Set aside the many hurdles to fighting AIDS effectively and one thing is clear: no "silver bullet" approach works everywhere. Creative approaches, sensitively executed by veteran leaders, are critical. This is one lesson that GADA and KICOSHEP have taught us.

If their work holds lessons for others, it's that addressing stigma is essential for mobilizing a broad-based and truly sustainable response to the AIDS pandemic. And groups with an extensive presence within their communities are often best at doing this.

In the sometimes chaotic social environments where the battle against AIDS is waged, it's also clear – as Maria Fernandes of Associação Saúde da Família (ASF) points out – that we must hunt continually for those creative, strong visioned groups, much like those molded by leaders in KICOSHEP and GADA.

The groups must be able to draw on counterpart contributions, local volunteers and local institutions. "That's what sustainable response means," she emphasizes.

Rapid Response Funds, we know, are finding fertile ground for innovation in six other countries. But the creative work done in Nairobi and São Jose do Rio Preto just may offer some helpful lessons for AIDS leaders around the globe.



A variation on GADA's anti-stigma theme (on a sticker).
The message: Hug a child with AIDS -- You won't get sick.