

Controlling HIV/AIDS in Our Community: The Story of Success in Il Ngwesi

Katharine Hagerman, CIDA IYIP Intern, hosted in partnership by ACEWH, GHO and the HSRC

This article will be published in the upcoming HSRC Review, which can be accessed through: www.hsrc.ac.za

Things are changing in the community of Il Ngwesi. In this Maasai area located about 300 km northeast of Nairobi, traditional leaders, women and youth are working together to take control of HIV/AIDS. “Olosho le’maa ematonyok aarare bittia”, the slogan of the innovative community-led Il Ngwesi Afya Program, translates as, “*Maasai people coming together to fight HIV/AIDS*”.

Il Ngwesi is remote. The population, who practice traditional Maasai culture, are socially, politically and economically marginalized from mainstream society. Nearly 9 500 people live in a 50 km² area around a collectively owned group ranch. Official leadership is all male, most families are polygamous and women and youth have less power in household decision-making than older men. Strong cultural traditions make talking about sexual health and HIV between ages and sexes taboo. Rising populations and environmental degradation place pressures on traditional pastoral livelihoods. Poverty and illiteracy rates are high; there are no developed roads in and out of the area and little access to water or markets for commercial goods. There are two partially equipped nursing stations but little access to HIV/AIDS prevention or treatment. All of this paints a bleakly familiar picture common to rural communities across the subcontinent. Socio-economic, cultural, environmental and political inequalities increase the risk and vulnerability of marginalized populations. But when it comes to HIV/AIDS, Il Ngwesi has a different story to tell.

In 2006, HIV/AIDS knowledge was low, stigma was pervasive, few people knew about HIV testing, fewer still had been tested and no one was living openly with HIV. A widespread belief existed that HIV/AIDS was a ‘town’ disease and did not affect the community. How is it that four years later: nearly 72% of the general population has received HIV counseling at least once and 56% have accessed HIV testing services within the community (31% more than once); over 200 volunteers have been trained as HIV/AIDS peer educators; community members are employed as project coordinators and HIV counselors; an anti-stigma declaration hangs in public spaces; young men talk about HIV/AIDS with their friends over beer; a mobile primary health care and HIV testing unit regularly visits the most remote corners of the region; and the Ministry of Health invites this socially excluded population to teach community engagement strategies to Public Health officials?

How, in light of deeply rooted social norms, has HIV taken precedence and caused a shift in the ability of people to talk about HIV prevention across sex and age-based groups?

“We were in a meeting and an elder said, “According to Maasai culture, the only time you can talk sexual matters to you daughter is when she is getting married. When you tell her, you will go to this man, and I want this man to be your husband and no other husband. So they said, the second day should be, when they were talking about HIV. If my daughter dies of AIDS I will cry. What is the need of me waiting until I cry, rather than saying today we’re going to speak about HIV openly, because I want you to be safe.” So, I also got that concept. I can talk to people about HIV/AIDS, we share together, we talk about it freely, we believe if you are my daughter or whatever you are, if I love you, then I should tell you.”

- Interview Participant

The key to success of the Il Ngwesi Afya Program is the sense of community ownership:

“Locally, there is a really strong pride that we were doing it ourselves, the idea that it was “our project” was critical to making it work.” – Interview participant

The program enables community members to address the HIV/AIDS risks they face. With a strong body of committed community members and partnering stakeholders who support the idea that local people know the solutions to their problems an HIV/AIDS intervention that addresses the specific needs of this community has been developed. And it is working.

How do we know this?

A recent participatory study evaluated the impacts of the Il Ngwesi Afya Program on a comprehensive set of indicators related to ‘getting HIV/AIDS under control’. Additionally, by asking what contributed to program success, the study articulated a model of how to develop a ‘sense of community ownership’. Two related articles explore the program impacts and processes of developing community ownership in greater detail (Hagerman, K. Forthcoming).

This study was undertaken in partnership with stakeholders, including community leaders, program staff and volunteers, the Institute of Cultural Affairs (ICA) Canada and the University of Toronto. Data was triangulated: a community-wide survey was completed with 100 households, in-depth interviews were held with 15 stakeholders and 10 focus groups were held with staff and volunteers.

How does the program work?

The program aims to control HIV/AIDS in Il Ngwesi and to build a model to inform the development of community-led HIV/AIDS initiatives that are sustainable, comprehensive and enhance regional and national strategies to make a lasting impact in communities underserved by government and other agencies. Activities are organized into four main areas: 1) Mobilization, Education and Awareness 2) Access to Core Services (PMTCT, mobile VCT, Care and Follow-up) 3) Community Building and Participation, and 4) Sustainability, Replication and Expansion.

What are the impacts?

Indicators to measure success were drawn from the relevant literature and existing program models. They provide a comprehensive assessment of the social and psycho-social determinants of 'getting HIV/AIDS under control' in Il Ngwesi, both at individual and collective levels.

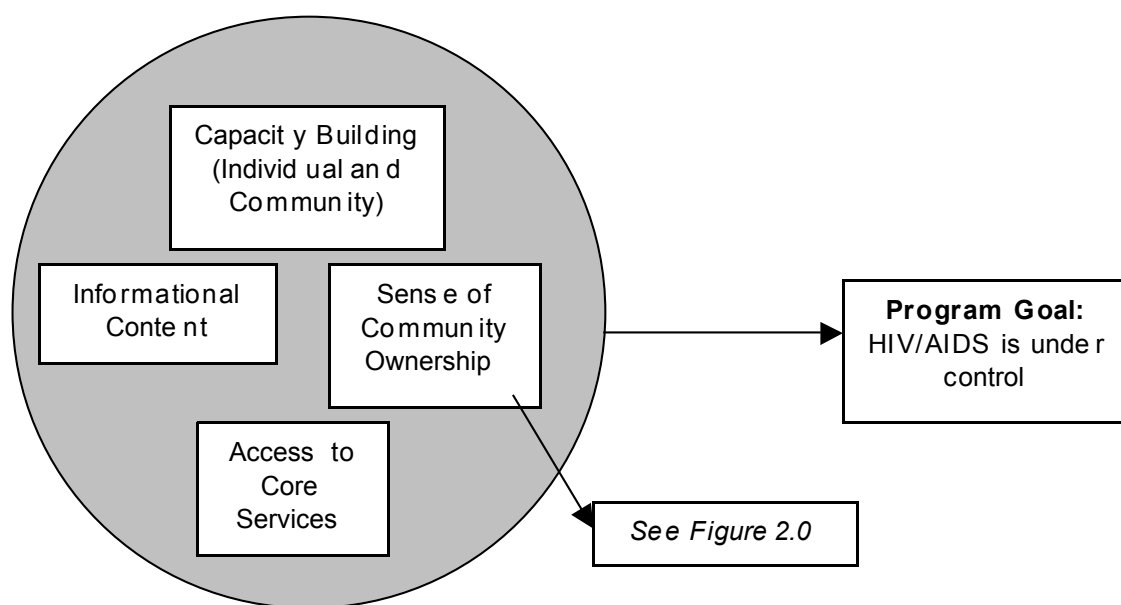
Success was demonstrated in:

Increased HIV/AIDS Knowledge; Widespread Individual Behaviour Changes in: Sexual Behaviour Change; visiting HIV Testing and Counseling Services and Changes in Traditional Practices; Capacity Building; Creating Safe Social Spaces for Dialogue (Decreasing Stigma); Community Volunteers; Provision of Integrated and Accessible Health Services; Co-operation with Voluntary Organizations in Prevention and Care; Building Solidarity; Building Confidence in Local Strengths; Promoting Ownership and Responsibility; Scaling-up: Strengthening, Replicating and Expanding for Sustainability; Comprehensive, Long-Term and Sustainable Program.

Why does it work?

The following four combined elements were evident wherever success was found:

Figure 1.0: Necessary Program Elements



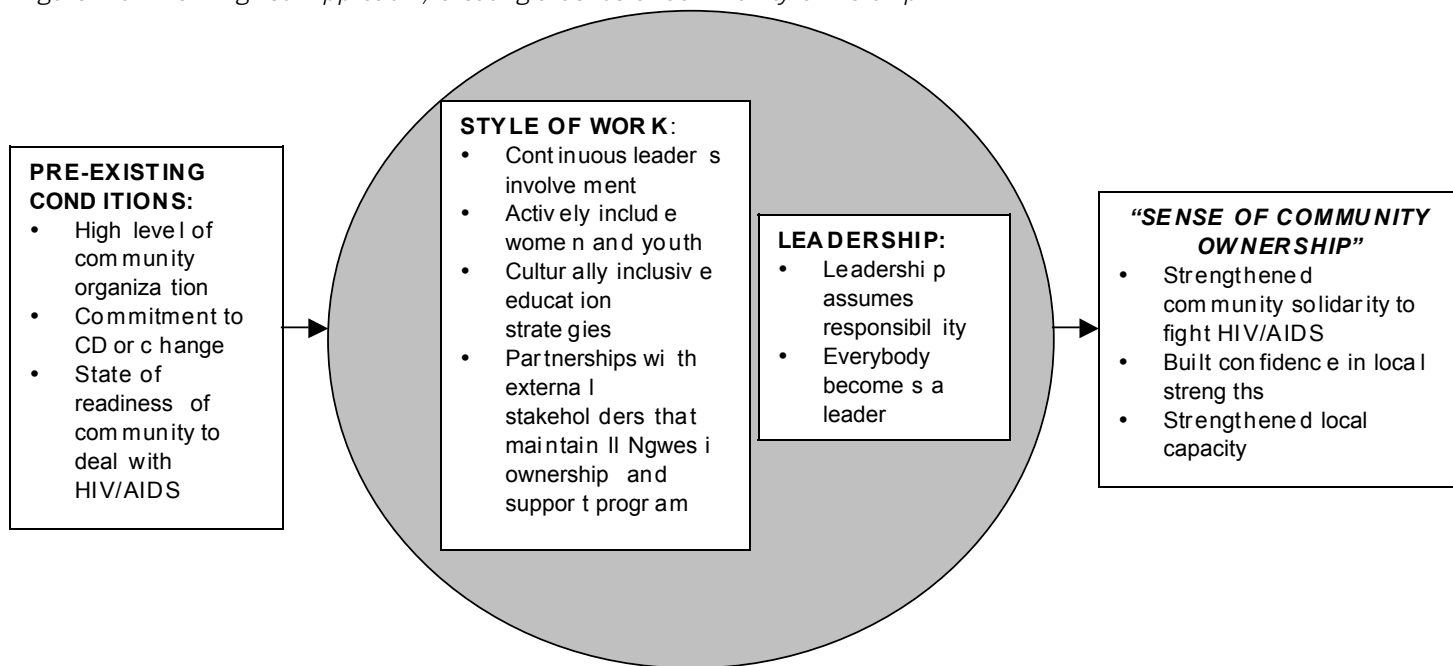
By involving community members in program design, HIV educational strategies included cultural traditions and values. A 'sense of community ownership' decreased stigma and encouraged widespread participation in program activities while engaging a spectrum of volunteers to become peer educators. This increased the reach and uptake of HIV education and core services to the community.

By developing this 'sense of community ownership', local people addressed their own needs, resulting in an effective and sustainable intervention.

"The lifestyle of the people and culture must be understood. Because whenever you take new things, which might be conflicting with culture, you'll always be met with resistance. And they'll be saying, 'this is their project, not ours'. And so, I think it's good that the project initiators, must understand people's lives, their needs, and when it comes to any project, it must be planned with the people who it is going to affect. People actually have solutions to their problems, when they give solutions, they'll take up their solutions, not the solutions being given by others"

- Interview Participant

Figure 2.0 'The Il Ngwesi Approach', Creating a Sense of Community Ownership



Implications for Application:

The lessons learned from the Il Ngwesi experience can inform public health initiatives in communities across Sub-Saharan Africa. Further critical study is needed to assess how the 'Il Ngwesi Approach' could be applied to different settings. For example, the 'Pre-Existing Conditions' and the involvement of traditional leaders were integral to the program's success in Il Ngwesi. These indicators may look different in new contexts, and should be assessed and included in strategies for working with local communities. This approach to community-led development fosters broader social change by strengthening solidarity or 'collective efficacy' (the idea that 'we can'), to fight HIV/AIDS and by addressing its broader determinants:

"In meetings, people use our example 'yeah we can do it like the HIV/AIDS program'- people think anything can be possible, if talking of this life-taking disease is possible, why not other things like creating water, which is a positive thing from the beginning?"
 - Interview Participant