

HIV/AIDS and community action: Now I know my Rights!

OVERVIEW

These briefing papers aim to summarise emerging findings from research undertaken by staff from the JEFCAS and other partners that may be of interest to those working in policy-making and development in Africa.

The research project was a collaboration between JEFCAS and Village-to-Village (Tanzania)

More news and views can be found on our blog at:

<http://jefcas.wordpress.com>

These briefings summarise longer and more detailed academic papers and are designed to make such research more accessible to a wider audience.

Anna Mdee, Paul Otieno and Lisa Thorley

This research explores whether activism by groups of people living with HIV/AIDS (PLWHA) to claim their rights is an effective way of reducing stigmatisation and improving access to Anti-Retroviral Treatments (ARVs) and other social protection such as food aid and free education.

BACKGROUND

HIV/AIDS is a major shock on livelihoods both in the loss of economically and socially productive individuals but also in the burden of care for the sick and their dependents that is entailed. HIV/AIDS also magnifies gender inequalities in that women are less able to avoid risky sexual contact but also disproportionately bear caring responsibilities and stigmatisation.

Our focus in this research was the nature and function of groups of People Living with HIV/AIDS in Tanzania (PLWHA) in Tanzania and in particular on PLWHA groups supported by a small NGO project to 'claim' their rights using a rights-based approach. Earlier studies have often seen PLWHA groups as weak and competing, for resources that *might* be accessible due to their status.



Group members meeting at agricultural project.

KEY FINDINGS

>Rights need to be clearly defined and owned by local institutions.

Where rights such as the right not to be stigmatised were clearly stated and linked to a fine. This proved to be effective at changing behaviour in the community.

>Rights are limited by livelihoods constraints.

Knowledge that PLWHA have rights to free ARV treatment is important and reduces corruption by health officials but is limited by the ability of the PLWHA to travel to obtain the medications and having a sufficiently good diet.

>Government is a very weak duty-bearer.

The local and national government response to HIV/AIDS has been undermined by large aid flows beyond its control. Local health, education and economic development services do not have the capacity to respond to requests for support from PLWHA.

2008 HIV/AIDS Prevention and Control Act (Excerpts)- Tanzania

5, (19) I. The Government shall, using available resources ensure that, every person living with HIV and AIDS, vulnerable children and orphans are accorded with basic health services.

24, (2). The Ministry shall, where resources allow, take necessary steps to ensure the availability of ARVs and other health care services and medicines to persons living with HIV and AIDS and those exposed to risk of HIV infection.

VII, 31. A person shall not stigmatize or discriminate in any manner any person on the grounds of such a person's actual, perceived or suspected HIV and AIDS status.

VII, 32. Any person who contravenes any provision (in relation to stigma) shall be liable to a fine of not less than two million shillings or to imprisonment for a term not exceeding one year or to both.

DATA COLLECTION AND PROJECT BACKGROUND

Village-to-Village (Tanzania) a small NGO working through links to the UK was awarded a grant of £33,000 under the UK Department for International Development (DFID) Civil Society Challenge Fund (CSCF). The project responding to the guidelines for funding applied a rights-based approach to work with PLWHA in two districts (covering 40 villages).

The aim of the project was to support existing and new PLWHA support groups access pre-existing representational structures such as the 'ward multi-sectoral AIDS committee' (WMAC). Such groups would be strengthened through working with members on their legal entitlements under the Tanzanian 2008 HIV/AIDS act. In terms of the project outcome the intended aim was to enable greater access for PLWHA to their entitlements under this act.

The V2V-Tz project has been operational with 45 groups in Moshi (24 groups) and Same (21 groups) districts since 2008. The DFID funding came to an end in March 2011 but V2VTz continues supporting the groups with advice as the critical consideration for the project design was that the groups should not be aid dependent and potentially cease to exist when the funding finished or cause further conflict over incoming aid resources. The data for this research was collected between November 2010-January 2011 using a semi-structured questionnaire, from 41 individuals who are active in different groups throughout the Moshi and Same Districts where the project operated.

HIV IN TANZANIA

Prevalence rates have declined to 6.6% for women and 4.6% for men (out of 15,000 people tested) (TACAIDS 2008) from 7.0% average in 2003/4. These figures are restricted to those over 15 so do not tell us about the prevalence in children who may have been infected in Mother to child transfer or through sexual abuse.

Accurate and disaggregated figures are very difficult to obtain and lack of data remains a significant challenge in a strategic response. It is known that roadside towns do tend to have much higher than average infection rates and the project under study included a number of towns and villages along the busiest intercontinental highway in Tanzania (Dar-es-Salaam-Nairobi highway) and therefore prevalence rates in the areas where the project operated are likely to be significantly higher than the national averages. A UNAIDS situation analysis for Tanzania from 2009 (latest available) suggested that there has been a significant increase in the numbers of people who can access ARVs (almost 250,000 in May 2009) (UNAIDS 2009). 250,000 still only represents approx 18% of the 1.4 million estimated by UNAIDS to be living with HIV/AIDS in Tanzania in 2009.



Solidarity through group membership

97% of funding for HIV/AIDS is from foreign donors and 86% of funding is off-budget and therefore beyond the control of the government. TACAIDS (2010:x) notes that 'national ownership is weak and accountability is poor'. Many donors pool resources through donor-created umbrella bodies such as the Foundation for Civil Society or the 'Rapid Funding Envelope', which has led to considerable resources being spent on a confusion of competing civil society projects rather than a systematic structural response. PLWHA groups are sometimes the only source of support and action at the local level.

Our research shows that an effective PLWHA GROUP should have the following characteristics:

- >Good leadership- meaning committed, fair and interested in benefiting the collective.
- >Value of regular attendance, participation, co-operation, unity, trust, respect, empathy, structure and rules
- >Having a livelihoods project that that all group members can participate in e.g. a farming project
- >Members have a nutritious diet as attendance can be affected due to an inadequacy in food consumption
- >Being active and not quitting.
- >Having hope and determination.

There is no doubt that the most successful groups in the project were led and inspired by charismatic individual leaders but successful groups also require that members have the bodily capacity and inclination to participate.

Eliza`s Story "Leaders are made, they are not born"

Eliza could easily be Tanzania`s pin-up girl for female empowerment. The image I remember of her vividly from my first meeting with her in 2008, in the rural village of Myamba in Same district is of her hiding her face from the camera during a meeting to introduce a DfID funded project in Myamba ward, she was one of the nine people living with HIV who had turned up for the meeting.

Eliza underwent training on capacity building, leadership, policy analysis, advocacy, rights and home-based care. She wasted no time getting out into her Community, sharing her story and encouraging others to be brave. She has facilitated the formation of 9 groups of PLWHA in Myamba Ward and the nearby Bwambo Ward.

Impressed by Eliza`s work, V2VTZ with funding from the USAID, bought Eliza a motorbike and placed her in an 18 month paid contract. Eliza reports that in a year, she has been able to reach about 3,000 people, she has established PLWHA support groups which are growing in number, and through her championing for the welfare of PLWHA, she has facilitated income generating projects such as chicken raising and goat rearing for some of the groups. The aim of these projects is to provide things like soap and food to PLWHA in the community who are in need of assistance. Eliza`s name sends shivers to government employees who she deals with, she is a champion to the PLWHA and the Myamba community. (Paul Otieno-V2V Project Manager)

THE BENEFITS OF KNOWING YOUR RIGHTS

Our interviews indicate a number of specific areas where an increased knowledge of the 2008 HIV/AIDS prevention and control act has made a difference to the experience of PLHWAs.

Interviews identified many positive advantages of using a rights-based approach as an organisation focus and the following reasons :

- >It permits you to advocate for your rights through legal channels
- >It permits you to advocate for your rights through applying pressure to local institutions
- >It allows empowerment. "Yes we may still be poor, however we are empowered"
- >"You leave a dark room and suddenly see the light".
- >Focal point to knowledge, we don't just know about our status.
- >No longer need to be subjected to corrupt health officials we know ARV's are free
- >Knowledge that our government are actually doing something and that we are not forgotten. Our lives count.

Access to ARVs continues to be constrained by the physical, financial and social capital required to reach the dispensing point. For a numbers of the PLWHA groups this was an issue of major concern and with the support of the V2V-Tz project they had held meetings with District HIV/AIDS co-ordinators to discuss more localised systems for accessing the medication. This issue is not necessarily resolved by a group approach as the issue of the drugs is also dependent on the individual medical status and particularly the CD4 count which requires monitoring. From our research many PLWHA groups do recognise this as a point of struggle and are advocating for improved access that tries to address the limited capacity of some to travel.

“

Prior to knowing my rights, I did not know that ARV's were free. I had refused to go to hospital for treatment. Having this knowledge has saved my life

“

Interviews in this research do suggest significant positive impacts from the specific 2008 act provisions on stigma, which states that a fine should be paid by anyone discriminating towards a person because of their status.

Several cases of these fines being levied and enforced by local courts were changing norms of acceptable behaviour in communities.

Some interviewees indicated that their livelihoods had been affected once people became aware of their status, however with extended dissemination of knowledge on the illegality of discrimination in the communities where project worked this has decreased.

Local distribution of food aid to PLWHA is another controversial issue and is a theme in many interviews. In one a women talks of being stigmatised by KIWAKKUKI (the local NGO distributing the food aid on behalf on WFP) .- however she does not want food aid she would rather get a small amount of capital to start a vegetable trading business.

“

Economic barriers means inactive members- some have left the group as they were not receiving enough to eat. They have been waiting over a year for food aid but their voice is not being heard

“

“

It is painful not being able to access your rights when you know them and when they are a legal entitlement. The problem with the government is we don't know where all the aid money is and what it has been used for?

“

There is some frustration at the slowness of a rights-based approach and particularly in relation to access to support and basic service. Interviewees speak of the frustration of knowing your rights but not being able to access them and that this can create stress.

POLICY IMPLICATIONS

For the 2008 Act to be fully implemented the (duty-bearer) Government of Tanzania needs to be able to respond to the entitlements laid out for the (rights-holders) PLWHA. It cannot do so when it has no co-ordinating or regulatory mechanism for interventions at the local level.

PLWHA groups are important in creating local visibility and support for PLWHA but they cannot be the only form of support. Not all PLWHA are willing or able to join a group and not all groups operate effectively. Those with active leadership can make some progress but support for PLWHA should not be dependent on this variable.

Consistent and clearly defined social protection is required at the local level in Tanzania. New technologies could offer a solution. For instance the M-pesa telephone money transfer system could provide a small allowance to allow for travel to ARV distribution points or to buy additional fruits and vegetables. Comprehensive and consistent social protection must extend to all those in chronic poverty and not just those living with HIV/AIDs.

References and Further Reading

This briefing is taken from a working paper: Mdee, A., Otieno, P. & Thorley, L. (draft) "Now I know my rights!" Exploring group membership and rights-based approaches for people living with HIV/AIDS in Northern Tanzania

Boesten, J. (2011). "Navigating the AIDS industry: being poor and positive in Tanzania." *Development & Change* 42(3): 781-803.

TACAIDS. (2008). "Facts and Figures/Statistics." Retrieved 16th December, 2011, from <http://www.tacaids.go.tz/strategic-documents/facts-and-figures-statistics.html>.

TACAIDS (2010). PUBLIC EXPENDITURE REVIEW 2007-2009 HIV AND AIDS Tanzania Mainland. Dar-es-Salaam, Tanzanian Commission for HIV/AIDS

[UNAIDS \(2009\). Tanzania: County Situation 2009, Joint United Nations Programme on HIV/AIDS.](#)