# IMPACT ASSESSMENT ON TRAINING OF RELIGIOUS LEADERS AGAINST HIV AND AIDS RELATED STIGMA, DENIAL AND DISCRIMINATION

Report of Study Findings

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## **ACRONYMS**

AIDS Acquired Immune Deficiency Syndrome

CBOs Community Based Organisations

**FBOs** Faith Based Organisations

FGD Focus Group Discussion

**HBC** Home Based Care

HIV Human Immunodeficiency Virus

IRCK Inter-Religious Council of Kenya

**OVC** Orphans and Vulnerable Children

**PEPFAR** President's Emergency Plan for AIDS Relief

PLWHA Persons Living with HIV and AIDS

SDD Stigma Denial and Discrimination

**USAID** United States Agency for International Development

#### **EXECUTIVE SUMMARY**

Despite major strides in the Kenya's National HIV and AIDS response since the 1980s, the HIV and AIDS pandemic remains a major public health challenge. HIV and AIDS related stigma is a major obstacle that limits the effective utilization of treatment and care services and undermines HIV prevention efforts. Reducing AIDS stigma is an imperative to the success of ameliorating AIDS-related suffering. (Hartwig et al, 2006)

In general, Stigma is a discrediting social label that changes the way an individual looks at him/her self and disqualifies them from full social acceptance. However, HIV has a particular, insidious stigmatization because it is associated with factors that imbue judgement and criticism. This "blaming the victim" increases the isolation and shame that the individual internalizes, which leads to fear of accessing services as well as psychosocial consequences (Wright et al, 2007). Stigma therefore contributes to the burden of illness and limits the effectiveness HIV and AIDS prevention and control. Stigma is therefore a matter of particular public health concern hence the need for effective interventions.

The Breaking Barriers Project, implemented by IRCK since 2006, funded by the United States Agency for International Development (USAID), sought to tackle, as one of its objectives, the HIV and AIDS related stigma to the extent to which it contributes to adverse psychosocial and physical health of OVC and their families in Nairobi and Nyanza provinces.

The specific activities included; training of 1,345 Religious Leaders in stigma reduction and advocacy skills to raise awareness on HIV and AIDS and promote positive living in their respective communities. Religious leaders are in close and regular contact with all age groups in Society and their voice is highly respected. Organised religion can exert a powerful influence on the priorities of Society and the Policies of its Leadership. Religious leaders can foster or mitigate HIV related stigma, depending on their degree of self empowerment. The key strategy conceptualized by IRCK, therefore was to build the capacity of the religious leaders to advocate against SDD by imparting skills through training.

The IRCK commissioned an impact assessment to establish the significance of the SDD training of religious leaders in the reduction of HIV related stigma. The specific objectives were to; track results and impact of SDD trainings conducted so far; gather measurable indicators to capture and inform on impact of SDD trainings and to prepare a report that will inform future programming and be used by religious leaders trained so far and other external persons.

Two focus group discussions were conducted, one in Kisumu and the other in Nairobi in the months of May and June, 2010 respectively. The findings of the assessment indicate that HIV related stigma is manifest in the sites of the project intervention and the training provided a strong impetus to the religious communities to intervene through activities and efforts aimed at tackling HIV related stigma and discrimination. The training empowered religious leaders to advocate against SDD. The leaders applied their enhanced knowledge and skills to educate their congregants on HIV and AIDS and to increasing play a key role in providing psychosocial support to PLWA.

## INTRODUCTION

The Inter-Religious Council of Kenya is a coalition of the Main faith communities in Kenya working through their Religious Coordinating Bodies. IRCK's main focus is to mobilize the joint resources of religious leaders for common action and in this Muslims, Hindus and Christians are able to work together to address/tackle various issues that affect the daily lives of the community.

Since 2006, IRCK has implemented the Breaking Barriers Project, Cooperative Agreement No. GPO-A-00-05-00017-00. This project was a three country project funded by the United States Agency for International Development (USAID), through the President's Emergency Plan for AIDS Relief (PEPFAR). The Breaking Barriers Project sought to reach at least 150,000 Orphans and Vulnerable Children (OVC) in the three countries and increase their access to education, Psychosocial Support and Home Based Care (HBC) through strengthening existing educational and religious institutions, resources and infrastructure. By March 2008, 139, 163 OVC had been reached.

The strategy of the Breaking Barriers project was to increase access to education directly by eliminating common barriers that keep OVC out of school, and indirectly by addressing the psychosocial and physical health needs of OVC and their families and by addressing HIV and AIDS related stigma. The project is implemented in Kenya by four partners; Pandpieri Catholic Centre, Rangala Child and Family Development Programme, St. Johns Community Centre and the Inter-Religious Council of Kenya.

Since 2006, IRCK has been conducting training on religious leaders on Stigma Denial and Discrimination associated with HIV/AIDS. The strategy has been mainly to equip religious leaders with skills and trainings which will build their capacity to advocate against SDD. Over 600 religious leaders have been trained so far by IRCK alone. More are being trained by RCBs who have adopted the course for their member.

IRCK developed a framework that is used to capture the impact of the training so far. This is meant to assist in future programs as well as give information on what the trainings have achieved on the grassroots level. There was thus a need to carry out an impact assessment on these trainings based on the framework produced and the trainings conducted.

## **CONTEXT AND METHOD**

Evaluations are conducted to learn from past interventions. Evaluations contain a process and an effect evaluation. The process evaluation checks all the decisions and the assumptions that programme developers have made and is important for the interpretation of the effect evaluation. The effect evaluation investigates the impact of the programme on determinants and behaviour that should be changed by the intervention. (Bos et al 2008).

The evaluation commissioned by IRCK on SDD trainings was an effect evaluation seeking to indicate the impact of the trainings as an intervention to tackle HIV and AIDS related stigma.

A review of the SDD training materials, training reports and other programme reports was conducted to provide a contextual background to the study. Two focus group discussions were conducted. The sample frame was constructed using purposive sampling methodology and individuals were selected from the list of trainees available at the IRCK.

The first FGD was held in Kisumu, at St. Teresa, Kibuye. At this FGD, 13 individuals participated. The second FGD was held in Nairobi, at IRCK offices and 11 individuals participated. The FGD sessions were coordinated by IRCK and moderated by the consultant undertaking this assignment.

The structure of the FGD sessions was guided by four main issues;

- i). The manifestations of stigma from the personal accounts of the individuals. The main focus of this theme for the discussion was to establish the level of stigma based on the encounters of the group and hence the significance of the intervention.
- ii). The determinants of stigma. This theme intended to establish the appropriateness of the approach to tackling the challenge of stigma employed by IRCK.
- iii). How the intervention addressed in particular the determinants of stigma.
- iv). Are there gaps and what are the recommendations?

## **RESULTS**

After clarifying the purpose of the discussions, the FGD sessions began by asking the participants to name manifestations of stigma in their communities. Participants identified two manifestations of stigma; self stigmatisation by PLWHA and public stigma. Public stigma refers to cognitive, affective and behavioural reactions that people have to PLWHA. Self stigma refers to the internalization of public stigma by PLWHA and involves diminished self-esteem, shame and feelings of needing secrecy in PLWHA.

The session revealed that some of the manifestations of Self Stigmatisation are fear of self expression and self exclusion, while some of the manifestations of Public Stigma identified were keeping one's distance from another who is coughing, especially in Public place, discomfort with sharing of seats with persons who appear physically weak or manifest visible opportunistic infections especially those affecting the skin, hair and mouth, gossip, labelling.

The participants were asked to name factors that fuelled stigma in their communities. The participants identified lack of in-depth knowledge on HIV and AIDS as a key determinant that fuels fears and misconceptions about HIV transmission. The fear of death and perceptions of personal responsibility are the other factors identified as fuelling stigma. Studies in developing countries have identified similar factors that influence stigmatisation of PLWHA (Ogden and Nyblade, 2005; Hartwig et al, 2006).

The discussion delved into the effect of the training on the religious leaders. The participants highlighted the empowerment of the religious leaders with correct knowledge and understanding about the disease. The participants emphasized the fact that religious leaders have become experts and role models after the training. Congregants and Community members make referrals are made to them for counselling and advice. Attitudes in the communities have changed, and relationships with PLWHA improved. However, the individuals were all at different levels concerning the degree to which they had assimilated the information during the trainings and their skills in utilising this information to train others, and intervene in individual cases of those requiring their services.

The major activities of the religious leaders in the post training period is increased advocacy, visiting the sick at home and in hospitals and training others on HIV and AIDS confidently. The major challenge cited was the lack of adequate resources with which to support the sick and the overwhelming magnitude of the numbers of PLWA requiring support.

Participants mentioned the following indicators that can capture and inform on SDD training impact:

- Strengthen the present monitoring and evaluation system
- Number of persons trained by those who are ToTs
- Number of ToTs trained (cascaded)
- No. of Persons Counselled
- No. the sick visited
- No. of persons who have attended awareness campaigns
- No. of PLWHA support groups established
- No. of those testing for HIV
- No. of VCT open days organised

## **DISCUSSION**

Studies have shown that interventions against AIDS related stigma are usually successful (Brown et al, 2003; Ezedinachi et al, 2002; Hartwig et al, 2006). These interventions could include information based approaches, coping skills acquisition, counselling approaches and contact with affected groups. In general, the review of interventions to reduce HIV/AIDS stigma suggest that the provision of information together with skills building is more effective than only the provision of information. Further, personal contact with persons with AIDS is one of the most promising approaches to reduce stigma on condition that it goes together with information about the disease.

The underlying objective of the SDD trainings is to empower religious leaders, who in turn mobilise their communities to tackle the AIDS related stigma challenge. Empowerment is an ideology that has emerged in reaction to the inadequacies in systems of care for persons with stigmatized health conditions (Dickerson, 1998). Empowerment may be modelled around three general attributes; self determination, social engagement and a sense of personal competence both at the individual and community level. It is instructive to explore the inclusion of empowerment indicators for SDD trainings and in the communities where trained religious leaders are active.

Research in Ethiopia, Tanzania (Nyblade et al, 2003) revealed that:

- i). Stigma interventions should create greater recognition about stigma and discrimination. People should become aware that Stigma exists, that can take certain forms, that it is harmful and that each person can contribute to reducing stigma.
- ii). Stigma interventions should provide in-depth knowledge about all aspects of HIV and AIDS.
- iii). Stigma interventions should create a safe environment to discuss stigmarelated values and beliefs, since it tackles difficult issues that are often taboo
- iv). Stigma interventions should use the language of the target population.
- v). PLWHA should be involved in AIDS stigma-reducing interventions at all levels. They have personal experience and knowledge that is needed to design appropriate AIDS stigma interventions and to educate other people about the disease and AIDS stigma.

#### RECOMMENDATIONS

The participants made the following recommendations;

- i). The involvement of PLWA in the trainings was commended as a best practice and should be enhanced at all levels. Personal contact with PLWA is one of the most promising approaches to reduce stigma and it strongly complements the information approach.
- ii). The SDD training could be structured progressive style. For example by introducing three levels; basic, intermediate and advanced. At the basic level, trainees could be aided to deal with common misconceptions that fuel HIV-related stigma, through an in-depth knowledge on HIV and AIDS. At intermediate level the trainees can be equipped with counselling skills and training of trainer skills. At advanced level trainers should receive adequate skills to conduct Home Based Care activities.
- iii). Regular refresher trainings should be held and participants require such a forum to share their lessons and learn from the others. There is a need to take into account the different competency levels of the participants when organising the trainings.
- iv). It was proposed that recruitment of participants for the SDD trainings should be demand driven in the sense that the participants are provided the opportunity to actively request for the existing slots rather than the present approach in which they are simply offered a place.
- v). The training should be scaled up to create a critical mass of religious leaders who are knowledgeable and can tackle SDD in their communities effectively. The present numbers are still small and cannot create the desired impact.
- vi). There is great need for partnership and collaboration at all levels to link and build synergies between the training and the implementation activities of the religious leaders and their faith communities to other interventions against HIV and AIDS in their communities, implemented by other partners.
- vii). There is great need to train chiefs and civil servants. Sometimes they are insensitive to the plight of PLWHA and do not help their cause.
- viii). The pre-test questionnaire used before commencing the training should be reviewed particular in areas where it appears to be insensitive to religious and cultural values. (It seems to create an impression that spouses cannot be trusted and that promiscuity is the norm and faithfulness is an exception).

ix).	. The toolkit used for reporting is complex and is not friendly to users, espec at the grassroots level	ially

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