



# **REPORT of the KAPSABET TRAINING WORKSHOP on COMMUNITY ENGAGEMENT in the CONTROL, MANAGEMENT & CARE of TB PATIENTS INCORPORATING A RIGHTS BASED APPROACH**

Held in Kapsabet, Nandi County, Kenya, March 20<sup>th</sup> To 22<sup>nd</sup> 2011

# ABBREVIATIONS

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AIDS . . . . .	Acquired Immune Deficiency Syndrome
ARV . . . . .	Antiretroviral
CBO . . . . .	Community Based Organisation
CSO . . . . .	Civil Society Organisation
DTLC. . . . .	District TB and Leprosy Coordinator
GoK . . . . .	Government of Kenya
HIV . . . . .	Human Immuno-deficiency Virus
KELIN . . . . .	Kenya Legal & Ethical Issues Network on HIV and AIDS
KNCHR. . . . .	Kenya National Commission on Human Rights
MDGs . . . . .	Millennium Development Goals
MoPHS . . . . .	Ministry of Public Health and Sanitation
MSM . . . . .	Men who have sex with Men
NACC . . . . .	National AIDS Control Council
NGO . . . . .	Non-governmental Organisation
PLHIV . . . . .	Persons living with HIV
PMTCT . . . . .	Prevention of Mother to Child Transmission
PPP. . . . .	Public Private Partnership
TB . . . . .	Tuberculosis
UNAIDS. . . . .	United Nations Joint Programme on HIV

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*Cover image: Lucy Ghati, TB Programme officer of NEPHAK, during a group discussion*

<b>NAME OF HOSTING INSTITUTION</b>	KELIN and NEPHAK		
<b>COUNTRY/SITE OF MEETING</b>	KEBEN CONFERENCE CENTRE, KAPSABET, KENYA		
<b>MEETING</b>	<b>COMMUNITY ENGAGEMENT IN THE CONTROL, MANAGEMENT AND CARE OF TB PATIENTS</b>		
<b>DATE OF MEETING</b>	20-22 <sup>ND</sup> MARCH 2011		
<b>TOTAL NUMBER OF PARTICIPANTS</b>	<b>MALE</b> 19	<b>FEMALE</b> 23	<b>TOTAL</b> 42

## 1.0 EXECUTIVE SUMMARY

The Kenya Legal and Ethical Issues Network on HIV& AIDS (KELIN) is one of the few organisations in Kenya and East Africa working on legal and human rights issues in relation to health and HIV. KELIN's goal is to undertake advocacy and provide leadership in ensuring an enhanced rights based approach in health and HIV strategies and programmes.

The **National Empowerment Network of People Living with HIV and AIDS in Kenya (NEPHAK)** is an NGO that unites support groups of People Living with HIV and AIDS (PLHIV) and individual PLHIV into a national and formidable force to counter the impact of HIV and AIDS on their lives and that of their loved ones in Kenya.

When Daniel Ngetich and Patrick Kipngetich; residents of Kapsabet were suspected of defaulting on their MDR-TB treatment last year, they were arrested and put in jail for allegedly posing a threat to the health of the Public. Fortunately, the two men were released in the interim, pending the full hearing, after the intervention of NEPHAK, KELIN and AIDS Law project, who filed a court case to challenge the constitutionality of the imprisonment. Nonetheless, the incarceration of the two men sent the wrong message and caused panic among other TB patients in the area. Consequently, this discouraged the number of people willing to undergo TB diagnosis and more seriously deterred defaulters of normal TB, and even those on ARVs, from seeking continued treatment.

It is clear that the negative social fear caused by misconceptions surrounding TB issues will require more investment in education and information in order to be reversed. To this end, KELIN and NEPHAK with support of the Open Society Foundation collaborated to deliver a three day training course in Kapsabet, Kenya, on human rights issues related to the control, management and care of TB, HIV and AIDS. The training was aimed at promoting a human rights approach to TB as a more effective avenue to stop the spread of TB; where the duty bearers and the rights holders are familiar with and appreciate their rights, responsibilities and obligations in the control, management and care of TB.

The training was aimed at strengthening the capacity of TB patients in the community, various representatives of government organs responsible for health, Community Health Workers (CHWs), area Chiefs, and other significant figures in the community who would be integral to the management of TB in the area.

The three days of training was enthusiastically attended by a diverse range of people from the Kapsabet community; 42 participants in total, 23 female and 19 male. There was intense discussion regarding TB, its causes, effects and treatment. Human rights issues related to HIV and AIDS featured significantly in discussions around TB, due to the very strong correlation between the two health concerns, and it was agreed that a united front is required to address both.

The representatives from the various government organs and area chiefs actively engaged in the discussions and contributed significantly during the training, with a view of addressing some of the issues raised in relation to TB in the area.

## 2.0 SUMMARY OF SESSIONS

### DAY ONE : INTRODUCTION TO BASIC CONCEPTS ON TB, HIV AND ASSOCIATED LEGAL AND ETHICAL ISSUES



*TB ambassadors, the area chief and the assistant chief follow the presentations closely*

*2360: Place where*

Anne Rono, the regional representative of NEPHAK, began the meeting and welcomed the participants to the training including the facilitators from KELIN and NEPHAK.

Day One began with an introduction to the training by Allan Maleche of KELIN, explaining that the initiative was aimed at bringing basic information to the community with the hope that the participants trained could relay the same information back to support groups, to the administrators, and the decision-makers in and around the Kapsabet area.

Lucy Ghati of NEPHAK outlined the definition of TB, drawing on input from the participants regarding their existing knowledge about the disease. She outlined TB's causes, how it is spread, and how best to manage the disease. The presentation included detailed medical information on signs and symptoms of TB, and about multi-drug resistant TB (MDR TB). Lucy emphasised the need to adhere to the full treatment program for TB despite the difficulties resulting from the lengthy treatment duration and possible side effects.

It was interesting to learn of the promotion of public private partnerships as explained by a delegate from the Ministry of Public Health & Sanitation (MoPHS). In this partnership the government provides essential medicines that are supposed to be dispensed free of charge and supplies them to private hospitals to enable people access them free of charge even in private facilities when you would otherwise be required to pay.

Lucy emphasised the need to follow TB treatment diligently and consistently. Dr. Sammy Rop, the DTLC – Nandi County, explained that various considerations inform the dosage; including nutritional issues and weight issues. He further elaborated on the procedure of defaulter tracing in the area. One of the former TB prisoners reported that because he had defaulted on his treatment he had had to start treatment all over again, and received too many injections, which was even harder than adhering to the treatment in the first place.

Nelson Otwoma of NEPHAK pointed out that TB in HIV positive patients may differ from those who are negative and may be harder to trace. Nelson advised CHWs to encourage them to go for regular TB check-ups for early diagnosis. He also added that they must be advised to be open about their status particularly to health service providers because the TB medication may at times not react well with HIV drugs.

Mr. Ropp again confirmed that Kenya does have drugs to treat extremely drug resistant TB, but explained that the same costs the government a lot of money. He explained that the government is supposed to pay for the drugs, and patients transport to go to the hospital and even provided patients with airtime to communicate any difficulties. He also enlightened participants on waivers available for TB patients whom the chief certifies are unable to pay for related health services. He explained that there were two social workers in Kapsabet responsible for assisting patients secure these waivers.

Unfortunately, majority of the participants were unaware of this provision and procedure. The few who were aware raised concerns at the complexity of the process of securing this waiver. Further, they raised doubt concerning the alleged 'freeness' of TB related services as evidenced by the feedback from NEPHAK membership to the contrary.

Willie Kibet, a CHW challenged the alleged recognition of the referrals by CHWs to health facilities.

*“Every time I refer people they come back and say that the people at the hospital asked who is he to refer you? Does he have qualifications to make a referral?”*

The doctor from the MoPHS recognized the existence of these barriers and encouraged the CHWs to report such incidences to the Area TB Coordinator.



*Dr Rop points out existing barriers in TB management in Kapsabet*

Following a short break the area Dr. Sammy Rop from the MoPHS was given an opportunity to present TB statistics in the area and pointed out the strong correlation with HIV. Lucy of NEPHAK then led a discussion on vulnerable populations in relation to TB.

The day was concluded by splitting the participants into groups discussions to analyse the factors that make both men and women vulnerable to HIV.

## *Group Responses*

### Group One: Vulnerability of Women

- Economically women are more often than not economically weaker than men and as a way of sourcing for income they put themselves at high risk of HIV.
- Social issues – during the birth process more often than not midwives come and sometimes the midwives are infected and put both mother and child at risk of HIV – home births without assistance, either way there is exposure to HIV.
- The fact that women are caring so that if someone is sick with TB the women will go there whereas the men may care less.
- Sexual violence against women especially rape which then leads to HIV infection.
- Low supply of female condoms.
- Female circumcision or genital mutilation and the use of the same tool.
- Wife inheritance.
- Polygamy.
- Women may be derailed spiritually not to take the proper medication as they believe they will be healed spiritually.
- According to our culture it is a taboo to talk about sex and therefore also about HIV because of the association with sex.

### Group Two: Vulnerability of Men

- Men have a don't care attitude.
- The nature of their duties – working in cement companies, construction sites, dusty places.
- Poor diet – they have to feed their wives and children first.
- Stress due to the responsibility of the family.



*Support group members solemnly digest the statistics of HIV and TB*

- Low rate of men who visit health centres unless they are bedridden.
- Men go to bars and discos which are social places.
- Stigma – men stigmatise themselves so people can't know they are HIV positive
- Cultural values – the man is the head of the home so if he discloses his HIV status that devalues him.
- Drinking alcohol and cigarettes exposes them to TB.
- Cleanliness – most of them are very dirty.
- Negligence – stopping to use medicine when you feel you are getting better.
- Men having side-spouses.

## DAY TWO: LEGAL AND ETHICAL ISSUES RELATED TO TB, HIV AND AIDS

Day Two started with a recap by Nelson Otwoma and Anne Rono from NEPHAK of Day One's sessions.

Allan Maleche of KELIN proceeded with an overview of human rights. The participants discussed their understanding of the meaning of 'human rights', children's rights, workers' rights, and prisoners' rights before the presentation.



*Alan and Melba of KELIN familiarise the participants on the rights and responsibilities regarding HIV and AIDS*

He outlined the characteristics of human rights and the limitations. The deliberations in this session interrogated the middle ground between individual rights and public health. Having agreed that the prison environment was not ideal for TB patients, the participants were concerned that despite being a high risk area there was no isolation ward in the area hospital. Participants felt it was important for relevant authorities to understand the circumstances surrounding non-adherence before action was taken. This would enable appropriate assistance and advice to be offered to encourage completion of medication.

The area Assistant Chief observed that before the training she was of the opinion that the TB defaulters ought to be locked away, but her opinion has since changed observing that it's the lack of knowledge that leads them to stop taking their medicine. She observed the effectiveness of TB ambassadors' discussions with patients observing that their message was more acceptable.

Following a short break, Melba Katindi of KELIN led discussions on stigma and discrimination by giving the facts of the case of *Midwa v. Midwa* No. 197/2000 [EALR] EA453 (CAK) drawing out the legal and ethical issues as understood by the participants. The participants had a very animated discussion as the facts of the case provoked strong reactions of indignation amongst many of the participants who had direct experience of similar issues. The case was a useful illustration of the way in which public perception drives stigma. Despite the continuous information, the participants observed that some negative perceptions still persist. The participants observed that in Kapsabet District Hospital there was still, though unofficially, a ward that is exclusively for HIV patients. It was common knowledge within the community that patients in this ward are HIV positive, and the implication is that most keep away from their relatives admitted in this ward for fear of infection.

Nonetheless, many of the participants from the Kapsabet community strive to 'live positively' in the hope of a better understanding amongst the community regarding the modes of transmission and the rights of PLHIV. TB related stigma however is an unaddressed struggle. Melba challenged the participants to think about how they as a community could deal with TB related stigma within the community.

After the lunch break Allan introduced the participants to legal and ethical issues related to TB and HIV interrogating the testing procedure in the local hospitals. He emphasised the need for informed consent prior to testing and provoked a heated debate on disclosure especially among discordant couples. The need for proper counselling to persuade the infected person to disclose their status to their partner was emphasized.

During the discussion on Public health and the transmission of TB the difficulty in balancing the right of the patient with the rights of the public was discussed. Melba outlined the case of *Airline v. School Board of Nassau County* 480 U.S. (1987) from the U.S. She explained that similarly, KELIN was interested in securing a precedent in Kenya that will clearly outline clear guidelines for protection of both the public and the individual rights with regard to TB. Melba concluded by explaining that legal and ethical issues relating to TB particularly highlighting related stigma and discrimination.

Melba gave an overview of the Bill of Rights particularly focussing on the right to health relating it to TB and HIV. She also highlighted the interdependence between the right to health with many other underlying determinants such as nutritious food, clean water, proper housing etc. However she was quick to point out that the right to health as other socio-economic right will be realised progressively over a period of time and with subject to availability of State resources.

The majority of the participants were familiar with the HIV & AIDS Prevention & Control Act 2006 (HAPCA). Melba gave an overview of the Public Health Act, Chapter 242 of the Laws of Kenya which provides for isolation of persons exposed to an infection and penalty for wilful exposure. She highlighted the concepts of human rights which prohibit forced treatment, but explained the strict legal circumstances under which isolation was legitimate. The day's session concluded after an intense question and answer session on the various legal provisions.

## **DAY THREE: CONTROL OF TB**

Nelson Otuoma of NEPHAK began the session with an overview of HIV and AIDS, the methods of transmission of HIV, and also demystified the myths around the epidemic. He outlined the



*Mr Otuoma of Nephak guides participants in the group discussions*

process of management of TB among PLHIV. This was followed by an overview of TB Vaccines by Lucy. She explained that primary prevention aims to prevent the infection. Secondary prevention aims to block the progression of the disease.

Lucy of NEPHAK divided the participants into three groups to discuss three case studies dealing with issues of stigma and discrimination. The purpose of the exercise was to examine the practical application of what the participants had learnt which resulted in lively discussions by the participants. The case studies were based on real life experiences of 3 of the participants for agreed to share their stories.

The key issues discussed from the case studies were discrimination, rights of OVCs and of People with disability living with HIV, role of health care service providers, use of TB support groups to enhanced adherence to treatment, mandatory testing, accessibility of health services and information, among others.

## POSSIBLE INTERVENTIONS AND SOLUTIONS SUGGESTED BY THE PARTICIPANTS

The participants identified the way forward as outlined below:

1. TB discussions in Community support groups and chiefs' barazas were encouraged as a way to sensitize the community and prevent reoccurrence of TB related arrests. It was suggested that the three TB survivors who were imprisoned should be initiated to become TB ambassadors because their experience would be of much value to the community and would be useful in reversing the negative effect of the imprisonment.
2. The need for continued education for the community regarding their human and health rights.
3. The support groups resolved to go into the communities and identify violations resulting from TB and HIV related stigma. The information should be relayed both to the chiefs and assistant chiefs for possible solutions and to KELIN and/or NEPHAK for follow-up.
4. The support groups should document the number of orphans in the areas and relay this information to the chiefs for further assistance in enabling them secure birth certificates from the DRO. Anne on behalf of NEPHAK will assist in filling out the forms for birth certificates. KELIN will be assist where necessary.
5. It was resolved that all the government representatives be invited to the community dialogue forum so that they can be made aware of existing community issues.

## 3.0 METHODOLOGY

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The training was conducted through power point presentations, and group discussion, including dialogue with representatives of government ministries, health professionals, and Chiefs from the local area. KELIN also undertook to forward the outcome of the training including all recommendations on the way forward in the form of a report. The Power Point presentations for this training can be accessed via the KELIN website.

# APPENDIX I: PROGRAMME



## Community Engagement In The Control, Management And Care Of Tb

In Kaben Hotel, Kapsabet on 20<sup>th</sup> – 22<sup>nd</sup> March 2011

### Objectives

- Introduce/ clarify basic concepts on TB
- Introduce/clarify basic human rights concepts
- Understanding the link between TB and HIV and vulnerable populations in light of both
- Understand the general legal and ethical issues raised by TB and HIV
- Enable an understanding of the link between Human rights, TB and HIV & AIDS
- Enable an understanding of the balance between Public health and Human rights in the context of TB and HIV
- Enable an understanding of the legal and policy provisions in relation to TB management
- Empower the community in comprehensive rights based knowledge on TB Treatment and other health rights
- Share the roles and responsibilities of the communities in the response to TB

20TH MARCH 2011		
TIME	SESSION	FACILITATOR
8.00 - 9.00 AM	Arrival and Registration	
9.00 – 9.30 AM	Climate setting: Welcome remarks and Introductions (name and key expectation)	NEPHAK
9.30 – 11.00 AM	Module 1: Overview of TB  (What is TB, Signs and Symptoms, Transmission, Diagnosis, Treatment, What is Multi Drug-Resistant TB - MDR)	NEPHAK
11.00 – 11.30 AM	Tea Break	
11.30 – 1.30 PM	Module 2: Impact of TB and HIV  Global epidemiology of TB and HIV (Infection rates), Kenyan National and local statistics.	NEPHAK/ Ministry of Public Health
1.30 – 2.30 PM	Lunch Break	

2.30 – 4.00 PM	Module 3: Vulnerable Populations and At Risk Populations in relation to TB General Risk factors (Gender - Gender and Gender Disparities in TB & TB in Women especially during pregnancy, Age - children, Poverty, Housing, Congestion, Transport), Connection between TB and HIV	NEPHAK
4.00 – 4.30 PM	Tea & Departure	
21ST MARCH 2011		
8.30 – 9.00 AM	RECAP	
9.00 – 10.00 AM	Module 4: Introduction to Human Rights (meaning; characteristics; general principles; underlying principles: Human rights and HIV & Human rights and TB - Relevant International Instruments)	KELIN
10.00 – 11.00 AM	Module 5: Stigma & Discrimination (Definition of Stigma, meaning of stigma, main causes of stigma, effect of stigma on TB and HIV programmes)	KELIN
11.00 – 11.30 AM	Tea Break	
11.30 – 1.00 PM	Module 6: Legal and Ethical Issues in the context of TB and HIV & AIDS (Human reactions to HIV & AIDS, Legal and Ethical Issues relating to testing, confidentiality, gender issues, biomedical research, TB in light of HIV, Criminal law in the context of TB and HIV, Public Health vs. Individual liberties (Autonomy)	KELIN
1.00 – 2.00 PM	Lunch Break	
2.00 – 3.30 PM	Module 7: TB Control and the Law in Kenya Legal system in Kenya, The Public Health Act, Relevant Guidelines/International Instruments, Government Policies, The role of the court process, Decided cases on TB Patients	KELIN
3.30 – 4.00 PM	Tea & Departure	
22ND MARCH 2011		
9.00 – 9.30 AM	RECAP	

9.30 – 11.00 AM	Module 7: Effective Control of TB (Diagnosis, Prevention, Management and Treatment, Importance of adherence to treatment, International standards in TB care and management , best practice community approaches, TB patient Charter, Role of Community in TB Management)	NEPHAK/KELIN
11.00 – 11.30 AM	Tea Break	
11.30 – 1.00 PM	Module 8: CASES STUDIES (Group work/discussion, Presentations)	NEPHAK
1.00 – 2.00 PM	Lunch Break	
2.00 – 3.00 PM	Way Forward and Community action Planning	KELIN & NEPHAK
3.00 – 3.30 PM	Awarding of Certificates to participation	KELIN & NEPHAK
3.30 – 4.00 PM	Tea Break & Departure	

## APPENDIX II: LIST OF PARTICIPANTS

No.	Name	Sex	Organization	Address
1.	John C. Mwei	M	Ass. Chief	P.O. Box 30 Kapsabet
2.	Joseph Kogo	M	Chief	P.O. Box 10 Kapsabet
3.	Anita Achieng	F	Safina	P.O. Box 110 Kapsabet
4.	Judith Atieno	F	CAAMAN PMTCT	P.O. Box 5 Kapsabet
5.	Norah Singoei	F	Kapsasur Baraka Support Group	P.O. Box 268 Kapsabet
6.	Roida Emba	F	Safina Support Group	P.O. Box 1027 Kapsabet
7.	Zekia Jeplosgei	F	Kamobo Widows G.	P.O. Box 24 Kapsabet
8.	Ann Muhamdia Bomdi	F	Kamatargul Support Group	P.O. Box 40 Kapsabet
9.	Ruth Tuwei	F	UPENDO Support Group	P.O. Box 369 Kapsabet
10.	Josphat Amoshe	M	Nandi Empowered People Living positive	P.O. Box 268 Kapsabet
11.	David Sirtui	M	St. Francis Ukweli Support Group	P.O. Box 369 Kapsabet
12.	Violet Chadota	F	Mwanro Support Group	P.O. Box 220 Kapsabet
13.	David Sitienei	M	G.K. Prison Support Group	P.O. Box 62 Kapsabet

14.	Christine Keino	F	G.K. Prison Support Group	P.O. Box 62 Kapsabet
15.	Betty C. Cheruto	F	Kamatargui Support Group	P.O. Box 1005 Kapsabet
16.	Wilbroda Otieto	F	Saffina Support Group	P.O. Box 1110 Kapsabet
17.	Bonface Amusavi	M	NEEMA Support Group	P.O. Box 1038 Kapsabet
18.	Anne Rono	F	NANDI Empowered RP	P.O. Box 488 Kapsabet
19.	Lucy Atieno	F	Olemica CBO	P.O. Box 1003 Kapsabet
20.	Hellen Jepatoo	F	Support Group	P.O. Box 85 Kapsabet
21.	Seli Chepkoech	F	Disability Group	P.O. Box 27 Kapsabet
22.	Salina Sang	F	Support Group	
23.	Henry Ngetach	M	TB Survivor	P.O. Box 15 Kapsabet
24.	Daniel Ngetich	M	TB Survivor	Kiminba
25.	Lydia Jemeh Tanui	F	Kenepote Support Group	P.O. Box 122 Kapsabet
26.	Silas C Maru	M	Disability is not inability Support Group	marusilas@yahoo.com
27.	Elwd N. Munyao	M	Min. of Planning	P.O. Box 360 Kapsabet
28.	Florence I Mbaya	F	Kapicangani Group	
29.	Ernest K Ruto	M	TB Survivor	P.O. Box 15 Kapsabet
30.	Willy Kipkemoi Kibet	M	Muitai Care Support Group	P.O. Box 13121 Nandi Hills
31.	Christine Sambu	F	Mutai Care Support Group	Nandi Hills
32.	Daniel Mgo	M	TB Survivor	
33.	Selenah Ngetich	F	Asst. Chief	
34.	Samuel K.Bittok	M	CACC-Coordinator	P.O. Box 1123 Kapsabet
35.	Sammy Rop	M	DTLC-Nandi	P.O. Box 5 Kapsabet
36.	John Mburu	M	Driver – Kim Tours	Eldoret
37.	Martin Maruti	M	Sayare T.V Eldoret	
38.	Victoria Chepkosgei	F	Kamobo T Group	321 Kapsabet
39.	Linda Tuwei	F	On behalf of CACC Coordinator	85 Kapsabet
40.	Patrick Nckirui	M	TB Survivors	
41.	Tecla Kimetto	F	DASCO	
42.	Willy Kipkemoi Kibet	M	Muitai Care and Support Ambassador of Hope	Kipkemoi.kibet@yahoo.com