



REPORT of the COMMUNITY DIALOGUE FORUM on HUMAN RIGHTS and the EFFECTIVE CONTROL, MANAGEMENT and CARE OF TB and HIV

Kapsabet, Nandi County, Kenya , on 23rd March 2011

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Cover picture: Women from the community were at the forefront of advocacy during the community forum

ABBREVIATIONS

AIDS	Acquired Immune Deficiency Syndrome
AMREF	The African Medical and Research Foundation
AMPATH	The Academic Model Providing access to Health Care
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
PMTCT	Prevention of Mother to Child Transmission
PPP	Public Private Partnership
TB	Tuberculosis
UNAIDS	United Nations Joint Programme on HIV

REPORT OF THE COMMUNITY DIALOGUE FORUM ON TB AND HIV IN KAPSABET, KENYA, MARCH 23, 2011

NAME OF HOSTING INSTITUTION	KELIN		
COUNTRY/SITE OF MEETING	KEBEN CONFERENCE CENTRE, KAPSABET, KENYA		
MEETING	COMMUNITY DIALOGUE FORUM ON TB AND HIV		
DATE OF MEETING	23 RD MARCH 2011		
TOTAL NUMBER OF PARTICIPANTS	MALE 25	FEMALE 35	TOTAL 60

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/AIDS (PLWHIVs) and individual PLWHIVs 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.

KELIN and NEPHAK, with support of the Open Society Foundation (OSF), collaborated to deliver a Community Empowerment Forum in Kapsabet relating to issues of Human Rights, TB and HIV. The Forum was held after a three days training also facilitated by KELIN and NEPHAK, which was organised in an attempt to respond to the negative impact that the imprisonment of three TB patients in Kapsabet had had in the community¹.

The objective of the forum was to mobilize complementary action by all stakeholders in the effective management of TB in the Kapsabet with a view to incorporating a rights based approach. The Forum brought together TB patients in the community, representatives of government ministries, 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.

Several of the participants gave an account of their stories including sharing various experiences, and the event was given significant media attention from Kenya Television Network (KTN), Citizen TV, Sayari TV, BBC radio and several newspapers including The Daily Nation on 25th April, 2011 and Taifa Leo on 24th March, 2011.

¹ The Kapsabet report on the community engagement in the effective control, management and care of TB is available at <http://kelinkenya.org/resources/>



Selina Negtich, the Assistant Chief of Kapsabet, shares her experiences in dealing with TB patients within her jurisdiction during the forum

Several participants shared their experiences of first contracting HIV, and the associated stigma, which was frequently compounded by further stigma due to succumbing to TB. For many of the female participants, HIV was strongly linked to their position in relation to men within Nandi culture. Many women reported having very little control over their own bodies, including a lack of freedom to choose when to have sex with their husbands, and impossibility in being able to ask a man to wear a condom, or to use a female condom themselves. For several participants with disabilities the stigma associated with TB and HIV was compounded by the social exclusion they experience in the community due to disability, and they reported increased difficulties in accessing health services. The high cost of medication, and the associated costs of transport to clinics to meet health appointments, was highlighted as a significant issue for most participants.

The Forum ended with a list of action points for the community to take forward the deliberations to enhance the ability for PLWH and TB patients to access their right to health care.

2.0. THE FORUM

Anne Rono, the regional representative of NEPHAK in Kapsabet, welcomed the participants, and the area assistant Chiefs introduced themselves, along with the forum panel made up of the Kapsabet Magistrate, the local area chief, a representative from the KNCHR and government representatives from various departments including Ministry of Public health and Sanitation (MoPHS), Ministry of Planning & Vision 2030, DASCO and CACC.

Daniel Negtich, a TB patient who was released from prison, gave an account of his story to the participants. Anne Rono, highlighted the benefits of the community capacity building conducted by KELIN and NEPHAK and emphasised the negative impact of TB-related arrests. She explained that there were various issues that needed to be addressed in TB management at community level. She welcomed further comments.



Daniel Ngetich and Patrick Kipngetich, the two petitioners in the court case, listen to the presentation

Willy: TB ambassador

"I am from Nandi East. TB badly affects old people, widows and orphans. TB affected me, other than the disease itself, even the medication had very adverse effects on me as an old person. I was already facing stigma as a result of being a PLWH. I am now a TB ambassador and in my work I have seen women who are widows from HIV and orphans who have been chased out of their compound, they don't know whether they are any laws to protect these groups. The community is struggling with ignorance and stigma. Thank you to KELIN and NEPHAK for coming into our community to assist us with difficult human rights issue. I request the government to take note of the importance of community education and information. It will empower us!"

Judith:

"I am a young woman PLWH. I had HIV and TB at the same time. I was pregnant and went through PMTCT treatment and as a result my child was born negative. I survived both HIV and TB. However as a worker in the PMTCT I attest to numerous financial challenges affect families access to such services. We are not aware of any waiver that exists to support them financially. It is key that this be addressed for effective management of TB and HIV."

Boniface:

"I am a young person and I am a survivor of both HIV and TB. I was diagnosed in 2006. I was helped by The Academic Model Providing Access to Health Care (AMPATH) who gave me medication and supported me. Until now I am healthy and I am even married. I am encouraging the hospitals to be more welcoming to the youth because the youth nowadays are very difficult and they need patience and youth friendly services. The issues of condoms should be openly addressed once a child is suspected of being sexually active. There is need for effective behavioural change among the youth and youth friendly services in health care provision."

Silus:

"I have a group representing persons with disabilities which is funded by The African Medical and Research Foundation (AMREF). In our community persons with disabilities are not perceived to be sexually active. TB facilities are not accessible for persons with disability. The facilities are not easily accessible in this area, especially for the visually impaired. People who are speech and hearing impaired cannot effectively communicate, particularly for diagnosis. The physically challenged have accessibility issues as well. We need to support existing effective interventions that have already been put in place within the community through additional funding to be able to address issues of persons with disabilities. All these issues need to be put into consideration when planning."

"When I got pregnant I went and got myself tested, and was diagnosed HIV positive. The doctors supported me and PMTCT resulted in my child being born negative. Initially when the women are diagnosed they are afraid of disclosing their status to their husbands. Women infected with both TB and HIV face double stigma. There is needs to be a lot of support given to them to address this issue within the community. The Chiefs need to address this issue at community level to encourage the husbands to be more supportive of their wives and issues of safe sex, especially the use of condoms."

3.0 WAY FORWARD

- Mr. Ropp; the District TB and Leprosy Coordinator DTLC representative thanked KELIN, NEPHAK and the KNCHR for organising the forum because it raised issues they were not aware of and which they will now address. He pointed out that they are still working together with TB patients who were previously imprisoned to ensure they complete medication, and termed their arrest as unfortunate. He reminded the community that rights come with responsibilities. Nonetheless, he raised concern about the lack of an isolation ward in Kapsabet which he explains leaves them little alternative for isolation. He promised to address the issues raised within his capacity.
- The area chief called upon the community members to regard the aspect treatment adherence as a personal responsibility in showing respect for other people's rights. She encouraged them to forward their community issues so that attempts may be made at addressing them. She committed her office to supporting the work of TB and HIV ambassadors in educating the people. She encouraged women not to fear disclosing results to their husband because we will initiate dialogue to ensure peace and safety. She reached out to for support in counselling services. She also promised to encourage pregnant women to attend antenatal clinics and ensure community support TB patients to ensure treatment adherence.
- Abdulkadir Lorot; the Principal Magistrate, Kapsabet Law Court graced the forum briefly stating that often decisions to imprison TB patients are made within the law. He said that the right to life must be interpreted in its totality. He however noted that most people are unaware of both their rights and responsibilities as dictated by law. He emphasized that one's

right cannot affect the rights of others. Hence the role of the judiciary to balance these rights. However he observed the Court's obligation to embrace human rights based approach in dealing with cases as enshrined in the Constitution.

- Winnie Moraa from KNCHR, who attended on behalf of Commissioner Winnie Lichuma declared the commitment of KNHCR in championing protection of human rights including health rights in Kenya.
- Allan Maleche of KELIN and Nelson of NEPHAK wound up the forum by acknowledging the need to advocate for improvement of adherence by addressing surrounding circumstances must be taken into account. They promised to highlight the needs identified to national level policy makers with the hope of getting sustainable solutions.
- The participants agreed to foster a stronger working relationship between the various stakeholders for more successful TB and HIV interventions.

Anne Rono delivered the closing remarks urging the participants to share the information they had received with the community.



Abdulkadir Lorot, the Principal Magistrate of the Kapsabet Law Courts, clarifies the role of the judiciary in TB management

4.0 METHODOLOGY

The Forum was conducted through group discussion including participatory dialogue among all stakeholders in the local area. The deliberations were guided by evidence from the personal testimonies from community members. KELIN also undertook to forward the outcome of the Forum including all recommendations and commitments.

5.0 CHALLENGES

Time limitation was a challenge as more participants wanted to share their experiences.

The turnout was more than had been anticipated and the so sitting space to accommodate all in attendance was a challenge.

6.0 RECOMMENDATION



Sally Kogo leads other participants from the community in presenting gifts of appreciation to the forum organisers

A progress review would be ideal to evaluate the impact of the forum on the community and the TB policies and procedures within the Nandi County.

APPENDIX 1: LIST OF PARTICIPANTS

Start time 11.00am

Venue: Nairobi Hotel Kapsabet

Date 23rd March, 2011

No.	Name	Sex	Organization	Physical Address
1.	Zekia Jepkos Gei	F	Kamobo Tumaini Widows Group	P.O.Box 24 Kapsabet
2.	Christine Sambu	F	Muitai Care Support Group	P.O.Box 120 N/HIUS
3.	Kipkemoi A.Kibet	M	T.B Ambassador, Muitai Chairman	P.O.Box 131 N/HIUS
4.	Caroline Owino	F	NEEMA Support Group	
5.	Janet Avikoshe	F	NEEMA Support Group	P.O. Box 1038
6.	Ann Bonbi	F	NEEMA Support Group	P.O. Box 40
7.	Sewnah Ngeitch	F	Alchief Kapsabet	P.O. Box 30
8.	Shadrack K.Sitienet	M	Alchief Kiminda	P.O. Box 30
9.	John C. Mwei	M	Alchief Kapwgetuny sub location	P.O. Box 30
10.	Bonface Amusavi	M	NEEMA Support Group	P.O. Box 1038
11.	Wilbrodah Ofefo	F	Safina Support Group	P.O. Box 1110
12.	Jane Ruto	F	NEEMA Support Group	P.O. Box 473
13.	Peter K. Miso	M	Kimmera	
14.	Eanest K. Ruto	M	Support Group	P.O. Box 15
15.	Julius Talem	M		P.O. Box 380
16.	Henry Ngetica	M	TB Survivor ICAPSDDET	
17.	David R. Sirtui	M	ST Franic URWELI Support Group	P.O. Box 369
18.	Ezekiel Chepsiror	M	Alchief Meswo sub location	P.O. Box 30
19.	Emmi Kavaya	F	PMCT Counselor	P.O. Box 5
20.	Daniel Nyetich	M	TB Survivor Support Group	P.O. Box 15
21.	Patick Kipnyetch	M	TB Survivor Support Group	P.O. Box 15
22.	Pius Kemboi	M	G. IL Prison	P.O. Box 62
23.	David Sitienei	M	G. IL Prison	P.O. Box 62
24.	Philimon Letine	M	ILABUTYE	P.O. Box 19
25.	Priscilla Metto	F	Chief - KIMIWDA	P.O. Box 665
26.	Hellen Cheatgo	F	C.H.W	P.O. Box 85
27.	Goret Atieho	F	Support Group	P.O. Box 110

28.	Anita Achieng	F	Community Health Work SAFINA Support Group	P.O. Box 110
29.	Atieno Judith	F	CAAMAM PMTCT Support Group	P.O. Box 5
30.	Norah Yego	F	Home Visitor Mother Franciscan	P.O. Box 268
31.	Zopporah Towe	F	C.K Prison New Tumaini Support Group Kapkangani	P.O. Box 62
32.	Florence Imbaya	F	New Tumaini Support Group apkangani	
33.	Roida Imbaza	F	Support Group	P.O. Box 1027
34.	Ruth Tuwei	F	CHW. Upendo Support Group	369
35.	Christine Keino	F	G.K Prison Peer Educator	62
36.	Zainabu Hussein	F	Safine Support Group	40
37.	Joash Keter	M	Musee wa mitaa Kiropket	15
38.	Edward Kiplagat	M	Teacher - Ngomuo Primary School	586
39.	Violet	F	Mwenzu Support Group	220
40.	Lydia J. Tanui	F	Kenepote	122
41.	Seli J. Cheproech	F	Disability Group	122
42.	Salima Sang	F	TB Ambassador	15
43.	Silas C Maru	M		0721303081
44.	Victoria Chepkosse	F	Kamobo T. Group	321
45.	Betty C. Cheruto	F	Kamutongi Support Group	1005
46.	Lucy Atieno	F	Olemila C.B.O	
47.	Matway Jamphu	F		30
48.	John Mbuw	M	KIMS TOURS	2013
49.	Jafe Ndungi	M	KIMS TOURS	2013
50.	Judith A. Mwanzi	F	Mwangaza Support Group	
51.	Joseph K. Kobi	M	Chief Kapsabet	30
52.	Meret Sughi	M	DASCO	5
53.	Linda Towe	F	CACC Coordinator	lindatuwei@yahoo.com
54.	Anne Rono	F	NEPLP	rono.anne@yahoo.com
55.	Martin Maruti	M	Sayare T.V	martinmaruti@yahoo.com
56.	Joy C. Negetich	F	Sayare T.V	ngetichiren@yahoo.com
57.	Ramedhan Tarus	M	Kapsabet D. Hospital	ramakipla@yahoo.com
58.	Abdulkadir Lorot	M	Principal Magistrate, Kapsabet Law Court	
59.	Sammy Rop	M	DTLC-Nandi	5
60.	Winnie Moraa	F	KNCHR	