



REPORT OF THE NATIONAL ADVOCACY FORUM ON THE INCORPORATION OF RIGHTS BASED APPROACH IN TB CONTROL, MANAGEMENT AND CARE

Held In Nairobi, Kenya On 18th August 2011

Prepared by Kenya Legal & Ethical Issues Network on HIV & AIDS,

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ABBREVIATIONS

AIDS	Acquired Immune Deficiency Syndrome
AMREF	African Medical & Research Foundation
CHW's	Community Health workers
DLTLD	Division of Leprosy, Tuberculosis and Lung Disease
DOH	Department of Health
DOTS	Directly Observed Therapy
DR-TB	Drug Resistant Tuberculosis
GF	Global Fund
HIV	Human Immuno-deficiency Virus
KELIN	Kenya Legal and Ethical Issues Network on HIV and AIDS
M&E	Monitoring and Evaluation
MDR-TB	Multi-Drug-Resistant Tuberculosis
MOF	Ministry of Finance
MSF-B	Medicines Sans Frontiers Belgium
MSF-F	Medicines Sans Frontiers France
NEPHAK	National Empowerment Network of People Living with HIV & AIDS in Kenya
NGO	Non-governmental Organisation
OSIEA	Open Society Initiative for Eastern Africa
PDR TB	Poly-Drug- Resistant Tuberculosis
PHO	Public Health Officers
RBA	Rights Based Approach
SSF	Single Stream Funding
T.B	Tuberculosis
TBSP	National Tuberculosis Strategic Plan
UNAIDS	Joint United Nations Programme on HIV/AIDS
XDR TB	Extreme-Drug-Resistant Tuberculosis

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PROFILE

REPORT OF THE NATIONAL ADVOCACY FORUM ON THE INCORPORATION OF A RIGHTS BASED APPROACH IN TB CONTROL, MANAGEMENT AND CARE, HELD IN NAIROBI, KENYA ON 18TH AUGUST 2011

NAME OF HOSTING INSTITUTION	KELIN and NEPHAK
COUNTRY/SITE OF MEETING	PANAFRIC HOTEL, NAIROBI, KENYA
MEETING	NATIONAL ADVOCACY FORUM ON THE INCORPORATION OF A RIGHTS BASED APPROACH IN TB CONTROL, MANAGEMENT AND CARE
DATE OF MEETING	18th AUGUST 2011
TOTAL NUMBER OF PARTICIPANTS	
MALE	14
FEMALE	24
TOTAL	38

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1.0 BACKGROUND

The need to protect human rights among the vulnerable populations has been identified as crucial in the national efforts on prevention, treatment and mitigation of the socioeconomic impact of HIV and TB. Human rights are about safeguarding human dignity and protection from adverse cultural and socio-economic vulnerabilities. Respect for human rights and the employment of the culture of working with respect for the principles of human rights (the Rights Based Approach) has been proven to enhance protection against violation of rights and mitigate vulnerabilities.

Nonetheless, health practices show a number of violations particularly in the area of TB and HIV management as relates to non-adherence to tuberculosis treatment. In most cases, the rights of patients are overlooked and public interest prevails over health related rights without taking into account the full circumstances leading to the default. The arrest and imprisonment of TB patients for defaulting treatment is one example of such violations. Such measures go contrary to the internationally recommended TB Patients charter which spells out the rights and responsibilities of TB patients and they send the message that Kenya is a country that is intent on criminalizing TB patients with defaulter records. This approach has since invoked fear in the general population particularly in Kapsabet and Mwea areas of Kenya.

These actions have further increased stigma and also undermined public health interests as many people have feared coming forward for TB testing and treatment and this has further posed greater danger to the public. A negative social fear has since been created which requires more education and information in order to be overcome.

Following the arrest and consequent imprisonment of Mr. Daniel Ng'etich, Mr. Henry Ng'etich and Mr. Patrick Kipng'etich Kirui in Kapsabet, KELIN and NEPHAK, with support from the Open Society Foundation initiated a program to engage communities through trainings and community dialogue fora on human rights and public health issues in the context of TB and HIV management. These forums were undertaken in Kapsabet and Mwea, in March and May 2011 respectively. Key issues for advocacy that touched on government procedures, policies and laws were raised at these forums. It is on the basis of the experiences gathered at these forums, reports of consequent arrests and imprisonment of patients in Kerugoya that CSOs working on health, HIV, TB and human rights issues resolved to conduct a one day stakeholder's workshop to discuss this important subject matter with the aim of achieving the following key outcomes;

- A clearer understanding of the negative effects of imprisoning TB patients and the use of the coercive model of TB control.
- An improved community and patient centred approach in National TB programmes.
- Increased dialogue between the stakeholders to ensure the prudent utilization of resources availed to improve the standard and care of TB patients.
- Initiation of a process to review and amend national policies, laws and guidelines that relate to TB management to incorporate a right based approach.

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2.0 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 & AIDS in Kenya (NEPHAK)** is an NGO that unites support groups of People Living with HIV (PLHIV) and individual PLHIVs into a national and formidable force to counter the impact of HIV & AIDS on their lives and that of their loved ones in Kenya. The overall goal of NEPHAK is to work to improve the quality of life of People Living with HIV & AIDS (PLHIV) through co-ordination of PLHIV activities in Kenya.

KELIN & NEPHAK with support from Open Society Foundation (OSF) conducted a one day stake holder's workshop on the incorporation of a rights based approach in TB control, management and care. The workshop was held as part of a series of programs undertaken by KELIN and NEPHAK, with support from the OSF to engage communities through trainings and community dialogue forums on human rights and public health issues in the context of TB and HIV management. These forums were undertaken in Kapsabet and Mwea, in March and May 2011 respectively.

2.1 SESSION I: EXPERIENCE SHARING

This session gave participants a brief background of the forum and highlighted its key objectives. Participants were appraised on the core issues the meeting sought to address, and personal testimonies on experiences in dealing with management and care of TB patients were heard from persons living with TB, persons imprisoned for defaulting on treatment, provincial administration, a representative of the judiciary and public health officers. A few members of civil society also shared their perspectives on the issues as well. The presenters in this session included Mr. Allan Maleche (KELIN), Mr. Nelson Otuoma (NEPHAK) Mr. Gerald Mutiso (Judiciary) and Mrs. Selina Ng'etich (Provincial Administration).

2.2 SESSION II: CURRENT STATE OF TB MANAGEMENT

The aim of this session was to hear and to understand the role and the programmes of the government in dealing with cases of defaulting patients with a view to interrogating their efficiency in line with International best Practices, hear the experiences of South Africa in dealing with defaulting TB patients with a view to borrowing from their successes and learning from their shortcomings and to come up with ideas on what can be done to improve the currently obtaining position in Kenya. In addition, during this session, participants were taken through the global fund expenditure in TB management in Kenya and its achievements and failures with a view to assessing the utilization of resources availed to improve the standard and care of TB patients.. The presenters in this session included Dr. Gachengo James (DLTLD), Angela Kageni (AIDSPAN) and Agnieszka Wlodarski (Section 27 & the Stop TB UNAIDS Task Force on TB and Human Rights)

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2.3 SESSION III: WAY FORWARD

This session mainly sought to crystallize all the various points of action put forth by the various actors. All participants were requested to contribute to the recommendations and way forward from the issues they had gathered from the discussions.

3.0 METHODOLOGY

The workshop was conducted through interactive processes including structured power point presentations, motion audio-visual presentations and question and answer sessions, including discussions with government duty bearers. KELIN undertook to forward the outcome of the meeting including all recommendations on the way forward in the form of a report in CD's circulated to all the stakeholders present and whose continued cooperation is vital in moving the process forward.

4.0 DETAILS OF SESSIONS

4.1 INTRODUCTION AND OVERVIEW

MR. ALLAN MALECHE - COORDINATOR, KELIN

Session 1 commenced at 0920hrs with introductory remarks from Mr. Allan Maleche, Coordinator of KELIN. Mr. Maleche gave a brief overview of the meeting and acknowledged the experience and expertise that the team of participants brought to the forum as members of civil society, community leaders, government duty bearers and TB patients.

Mr. Maleche noted that this forum was organized on the backdrop of the experiences that KELIN and other organisations including TB patients have had, for defaulting on their treatment. He stated that these are issues that touch on inter-alia human rights, law enforcement and government policy. In order to put the forum into perspective, Mr. Maleche shared three case studies with participants, of TB patients who had been vilified and/or imprisoned for defaulting on their treatment.

Case 1 involved a TB patient who was imprisoned in Nandi County for skipping his treatment of TB. According to the patient, he was imprisoned for failing to follow the doctor's instructions. Mr. Maleche stated that the imprisonment was done on the basis of the Public Health Act. Ironically, the patients were detained in an overcrowded prison in general population and without a proper diet. This case caused a lot of controversy both internationally and locally.

Case 2 involved a 55 year old man, Mr. Benson Mutugi who was equally jailed for 8 months by a Baricho Court in Kirinyaga County for having defaulted on his treatment. According to Mr. Muturi, the Public Health Officer Kirinyaga County, Mr. Mutugi had defaulted on his medication severally hence making it difficult to contain the spread of the disease. The Public health officer stated that his officers had the resources to make visits on all TB Patients, to see whether they were following their medication rules and any defaulters would be isolated until they completed their doses. Ironically however, the public health officer had no allocations for TB education for sensitization of the public.

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Case 3 involved a 28 year old herdsman from Nanyuki in Laikipia County, Mr. James Kasana who was jailed for one year for refusing to take his TB medication. According to Mr. Kasana, he skipped his TB medication for 10 days as he had no access to food, and when he took his medicine he would get dizzy, and at times would collapse after getting the injection. He asked his family members to provide him with at least two meals a day but they couldn't afford it.

A 5 minute video was shown to participants of three brothers in Kapsabet diagnosed with TB, one of whom was present at the workshop, who had defaulted on treatment. The video highlighted socio-economic challenges that the three brothers faced prior to imprisonment and those consequent to the imprisonment. Poverty and illiteracy came out as the two major obstacles to adherence.

In summary, Mr. Maleche stated that these were just a few of the cases of TB patients being imprisoned in prison cells with poor ventilation and poor diet for defaulting on their treatment. The question that then arises is this; **are prison cells the right place to isolate TB patients who default on their treatment?**

Mr. Maleche outlined the overall objectives of this workshop as follows;

- To hear first hand experiences of members of the community and civil society organizations in matters relating to detention, isolation and imprisonment of TB patients with a view to evaluating the key challenges to adherence.
- To understand the role and the programmes of the government in dealing with cases of defaulting patients with a view to interrogating their efficiency in line with International best Practices.
- To come up with clear and practical recommendations to address the challenges and gaps.

4.2: SESSION I: EXPERIENCE SHARING

The following experiences were shared at the workshop by TB patients who had been imprisoned for defaulting on their treatment.

4.2.1: Simon Maragua from Kirinyaga County

Mr. Maragua was diagnosed with TB in March 2010. His Doctor instructed him to take his medication without skipping any. He faithfully followed the Doctor's instructions for four (4) months after which he went for further tests. His results were not explained to him and upon inquiry from a friend he was told that his lab results indicated he was TB Negative which he interpreted to mean he was cured. However, the disease later re-surfaced. He started going back to the local health center for medication but then the center was always closed on weekends and so he had to skip his medication on those two days.

The only available health center on weekends was in Kerugoya town but it was too far away and he couldn't afford the transport cost of Kshs 300 to take him there. When he was finally able to see a doctor and narrate his ordeal, he was marked as defaulter and reported to the public health officer who then sought his arrest. He was not informed of the legal action that was to be taken

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Community representatives Simon Maragua and Cyrus Maru share their experiences during the forum

against him. He was later arraigned in court and sentenced to 8 months in prison. While in prison, he stated that he was only provided with porridge and injected daily with very strong medication. Although the doctor had prescribed a special diet for him, the prison warden informed him that they could not provide him with the same as they could not afford it. Two months after his incarceration, He was visited by officers from KELIN who offered him legal aid and secured his release from prison. He says he still adheres to his medication and urged those diagnosed with TB to do so too. He urged health service providers to be more diligent in arming patients with clear and accurate information on any medical procedure or medication being administered stressing that no-one wants to die and no one having gone through this sickness, would ever want to intentionally transmit TB to others.

4.2.2: Lucy Waithera from Mwea, Kirinyaga County

Ms. Waithera was a TB patient and had been on medication for 8 months. She defaulted on her medication on the belief that she had received spiritual healing only to be re-infected again. She got very ill to the extent that she could not walk or even stand. She was visited by NEPHAK and officers from other organizations, who spoke to her and took her to hospital where she was asked to repeat her medication for 8 months in addition to 60 injections as part of her treatment. The difficulty she sighted of re-treatment was that she had to visit the hospital daily for her treatment. However during weekends when the facilities remained closed, she

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stated that she had to pay doctors to attend to her because the local clinics were closed. Despite this obstacle, she received so much emotional support and was able to complete the dosage. She is now healed

4.2.3: Cyrus Maru from “Disability is not inability Group”, Kapsabet

Mr. Maru shared his experiences in relation to persons with disabilities. He stated that generally, persons with disabilities face momentous challenges in accessing health care and facilities in most public hospitals. The physically challenged find it difficult to cover the long distances to health facilities and when they arrive there mobility to access the different units of the facility is limited by the kind of infrastructure set up. The deaf have difficulty in communication with health workers who are not properly trained for that purpose. Health facilities are not equipped with sign language materials for the deaf. The blind lack braille facilities and this makes it difficult to properly adhere to prescription and the mentally impaired persons also lack full time support that they require.. In addition, he stated that healthcare workers have a negative attitude toward persons with disability and this is a major cause of stigma amongst such patients.

4.2.4: Selina Ng’etich - Assistant Chief, Kapsabet

Ms. Ng’etich outlined her main official duty as being to protect life and property. She stated that everybody has a right to life, health and education. In her areas of jurisdiction, most of the time when patients are too sick and bedridden, most families hide them and in such cases, her office mobilizes community health workers to attend to them. Her office also educates and sensitizes the public on inter-alia public health issues during public barazas. She highlighted the following challenges in the discharge of her duties in relation to public health;

Most officers in local administration are not aware nor are they sensitized on issues around HIV & TB. She urged that this group should be involved in any sensitization initiative whether by government or by local and international NGOs

Traditional and Spiritual Healing is a difficult issue to address within the community as it is part and parcel of customs. Some patients mix herbal medicine and hospital prescriptions hence making adherence challenging. Some stop taking medication altogether believing they have received spiritual or other healing.

There are very few public health officers for purposes of health education. One PHO covers such a broad area making them largely inaccessible to the public.

4.2.5: Mr. Gerald Mutiso – Magistrate, Kapsabet

Mr. Mutiso shared his experiences and challenges in the judiciary in dealing with TB management and control in his area of jurisdiction. In Mr. Mutiso’s presentation, the following salient issues were highlighted;

- Fundamental human rights and freedoms are inherent and are an entitlement with or without the constitution.
- When confining a person, certain fundamental human rights and freedoms are denied to that person.
- Freedom cannot be deprived without just cause and this therefore begs the question; *is failure to take medicine a just cause?*

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Mr. Gerald Mutiso; a Magistrate and Ms. Selina Ng'etich; an assistant chief, both from Kapsabet highlight the difficulties faced by duty bearers

- Rights must be enjoyed with limitations as to duty to respect the rights of other persons. This includes the right of other persons to a clean environment. Statutes that govern this right include the Public Health Act Cap 242 Laws of Kenya.
- Section 27 of the Act empowers a magistrate to order isolation of a person who has been exposed to infection and who is likely to spread the disease to other persons. He however provoked debate around the use of this discretionary power;
- “Does isolation mean Detention? Is there a feasible alternative to jail term? Do magistrates make further enquiry on the efforts made by the PHO to ensure adherence prior to presenting the defaulter before court?” These were areas he sighted needed further debate.
- Poverty and hunger are a common occurrence and greatly impact on adherence of TB patients. Should mitigating factors be taken into consideration during these cases?
- Questions often abound as to the effect of confining TB patients in congested prison cells with no proper diet. No proper policy has emerged as yet on this aspect of public health
- In his concluding remarks, Mr. Mutiso opined that Imprisonment of TB patients should not be taken literally to mean or to imply incarceration because magistrates are often caught between releasing defaulters and protecting public interest.

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4.2.6: Implication of Imprisonment and Detention of TB patients in National TB Control

MR. NELSON OTWOMA – EXECUTIVE DIRECTOR, NEPHAK

Mr. Nelson Otuoma of NEPHAK made a presentation on implications of imprisonment and detention of TB patients in the national TB control. Mr. Otuoma began by noting that in very rare cases is defaulting deliberate. He regretted to note that where defaulters are arrested, the information given to the public is often misleading and meant to instil fear while at the same time stigmatising arrested TB patients. In his presentation, the following main points were highlighted;

- The arrest, prosecution and subsequent imprisonment of two TB patients in Kapsabet generated a lot of interest (community and media). Other cases of arrests have been reported in Mwea, Kilgoris, Iten, Nanyuki and it is believed that many more TB Patients are today held ‘somewhere’ but this has not been reported (by the media).
- There seem to be no consensus on how to handle TB Patients who default on their treatment
- Defaulting is not always refusing; it is not always deliberate.
- Most TB patients default for a variety of reasons including; lack of proper explanation from doctors on importance of adherence to medication, limitations of medication that tie patients to a certain geographical area despite their socio-economic circumstances, perception that TB is related to HIV, the nature of TB drugs, lack of food and mistrust and competing religious and cultural beliefs.
- Mandatory detention is an extreme strategy and is based on a historically coercive model of TB control. When isolation or mandatory detention is done at prisons (after court), the implications may include; Fear and anxiety among patients and their families, guilt and stigma which dis-empowers TB Patients, confusion and misinformation about TB and HIV in prison, communities etc, TB suspects, especially those infected with HIV may not volunteer to be screened or tested for TB, TB Patients who default and who would otherwise seek re-treatment may not come up, enlisting the support of the community to arrest defaulters may be counterproductive, Prisoners may not understand this new ‘crime’

In conclusion Mr. Otwoma stated that Courts and prisons are not well equipped to deal with health and TB issues.

This session ended at 1130 hrs

4.3 SESSION II: CURRENT STATE OF TB MANAGEMENT

4.3.1: The role of the government in ensuring community and patient participation in National TB programmes

DR. GACHENGO JAMES – DLTLD, MINISTRY OF PUBLIC HEALTH AND SANITATION

Session II commenced at 1150hrs whereupon Mr. Maleche invited the representative of the Division of Leprosy, TB and Lung Disease (DLTLD) Dr. Gachengo James to make his presentation on “*The contribution of the government in MDR-TB management.*” In Mr. Gachengo’s presentation the following salient issues were highlighted;

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- According to the Millennium development goals, we are supposed to halve TB cases in the country by 2015 and eradicate TB completely by 2050. Majority of TB patients in Kenya are managed in public health facilities and only 6% in the private sector.
- TB increase in the country can be attributed to a number of factors including; Poor housing, overcrowding, poor ventilation, malnutrition, poor access to health care and poor quality of health care.
- DR TB screening began in 2003 and since then 531 cases have been diagnosed. Of these cases, 267 MDR TB, 6 PDR TB, 2 XDR TB patients have been initiated on 2nd line treatment.
- Surveillance of DR TB patients has steadily increased over time. In the new strategic plan the country plans to start screening of all retreatment cases, all DR TB contacts, all HIV positive TB smear negative cases, all smear positive cases and all HCWs diagnosed with TB.
- The number of MDR TB patients has been on the increase since 2006 but the trend has slowly been reversed since 2009. As at 2010, the number of MDR TB cases stood at 112 down from 150 cases in 2009.
- Nairobi and Nyanza account for the highest number of MDRTB's in the country while North Eastern Kenya has the lowest number of cases with only one patient.
- There is only one central reference laboratory for screening of TB and this translates to excessive delays on obtaining results hence treatment and prevention.
- The government in its efforts to decentralize health facilities for MDRTB patients has established 62 facilities countrywide up from only 4 facilities as at 2008.
- In particular, the government is embracing the gene Xpert technology to ensure faster screening and hence results. At the moment, there are already two gene Xpert facilities in the country run by MSFF and MSFB and are already in use in Mathare. The government has sufficient drugs for MDRTB patients in the country including N95 masks. It is also supported by other international non-governmental organizations including MSF-F, UNITAID, and GF.
- In addition to medicines, the government provides support for patient in terms of transport, patient investigations, airtime for health care providers for communication purposes, contact Tracing and health education at the patient's home and defaulter tracing services.
- There are still challenges as regards patient isolation units and inadequate trained staff to cater for the rapid decentralization of services.

Dr. Gachengo's presentation ended at 1310 hrs.

4.3.2: Analysis of Global Fund Expenditure in TB Management in Kenya

ANGELA KAGENI - AIDSPAN

Mr. Maleche then invited Ms Angela Kageni of AIDSPAN to make her presentation on “*Analysis of Global Fund Expenditure in TB Management in Kenya.*” Ms. Kageni's presentation mainly gave a snapshot of the amount of money Kenya has received from the Global fund with a view to establishing whether there has been prudent utilization of the resources available to improve the standard and care of TB patients. This data is available and accessible to members of the public from the global fund website. In essence, Ms. Kageni's presentation highlighted the following key issues;

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- Funds that were disbursed to Kenya in round 2 of the global fund were used mainly for Training laboratory technicians and CHWs in management of TB cases, scaling up TB service in marginalized areas & TB/HIV collaborative activities, urban TB control Strategy, procurement & distribution of TB drugs, developing guidelines for TB control in the Private Sector and IEC and community sensitization on general TB knowledge, operational research and improved surveillance.
- Round 2 received a no go in 2005 from the Secretariat when applying for Phase 2 due to inadequate implementation. Although this decision was lifted by the GF board and Phase 2 granted, there were no further disbursements made.
- Funds released for round 5 of the global fund were mainly to be used for Robust community awareness/ sensitization/ advocacy programmes including; several treatment related activities, strengthening community's capacity to respond to the stigma and TB epidemic through training and awareness campaigns, construction of an isolation facility at Kenyatta National Hospital, and developing relevant IEC materials. Unfortunately, the isolation facility was never built and the round received a "C" rating i.e. not acceptable.
- Round 6 also had components relevant to activities on training Round 6 also had some relevant activities such as training for MDR TB, health planning and management, M&E, training for laboratory staff, health care workers, and community health workers.
- Rounds 5 Phase 2 and Round 6 Phase 2 have been consolidated into the MoF's Round 9's Single Stream Funding (SSF). The two SSF grants (i.e. MoF and AMREF) technically, are currently the only operational grants for TB.
- The key activities under the SSF 11 grant under MoF include; strengthening TB control by identifying the needs and defining priorities for the three levels of TB infection control i.e. administrative control measures (policies and work practices), environmental control measures, and personal protective equipment (respiratory protection) Providing technical support to carry out an extensive assessment of all major hospitals, prisons and laboratories, developing new IEC materials on TB control, leveraging CSOs to strengthen DOTS, providing peer-to-peer education in the workplace, training health staff and CHWs on MDR-TB, TB/HIV collaborative activities and PAL.
- Key activities under the SSF 11 grant under AMREF include; training CHW on treatment adherence activities, screening TB patients and PLWHA, community based DOTS, nutritional assessment and management, procuring and training health workers to use nutritional assessment tools providing nutritional support, educating TB patients (health education, including infection control), home visits included.
- Treatment, diagnosis, case management and control activities targeting health facilities and officers, were significantly covered; however linkages at the community level are limited.
- A large number of activities covered in Rounds 5 and 6 do not have significant coverage in the SSF grants for instance, activities that address a wide range of community sensitization or advocacy programmes such as: those addressing the protection of patients' rights; addressing stigma & denial, those directly engaging with communities to raise awareness about TB prevention and control, and those that actively engaging civil society organizations in implementation at the local level.

4.3.3: The Link between TB & human rights in relation to detention of defaulters

AGNIESZKA WLODARSKI – ATTORNEY, SECTION 27 / MEMBER, UNAIDS STOP TB TASKFORCE

At 1430 hrs Mr. Maleche invited Agnieszka Włodarski an Attorney at Section 27 in South Africa & the Stop TB UNAIDS Task

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Force on TB and Human Rights to make her presentation *“The Link between TB & human rights in relation to detention of defaulters; The South African Experience and the International Standards and Best Practices”*

Ms Wlodarski stated that there are complex linkages between health and human rights. The following key issues were highlighted in her presentation;

- Violations or lack of attention to human rights can have serious health consequences such as access to socio-economic rights such as adequate food and nutrition.
- A rights based approach is a useful tool for government when health-related policies and programmes, including around TB, are to be designed, implemented, monitored and evaluated, (as was the case in the SA MDR TB treatment policy) and in developing a framework for health development.



Ms. Agnieszka Wlodarski engages the participants on practical alternatives for TB management in Kenya

- South Africa does not resort to court anymore to get patients who have absconded to return to DR-TB specialised hospitals – but is developing new policies that recognise human rights such as increasing numbers and ability of hospitals to cope. SA does not arrest defaulters.
- In the TBSP 2007 – 2011 the DoH presentations recognise the role that poverty plays in adherence to treatment and this is something that the DoH TB Management Cluster is working to address.
- Drug resistance can develop not only as a result of a patient defaulting BUT can also be as a result of the health system (e.g.

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drug stock-outs) OR as a result of the specific situation of patients (i.e. living in poverty and not having access to adequate food and water to keep taking their treatment).

- South Africa also has primary infections of MDR-TB as a result of poor infection control in facilities and where many live in conditions of poverty (i.e. A whole family in one small tiny house).
- Education is crucial to encourage treatment seeking behaviour and empower patients while coercive action, forced isolation or arrests, which perpetuates stigma drives the epidemic underground and does not address the underlying issues and is not sustainable.
- The Department of Health is legally responsible for control of TB, including DR-TB, as a public health issue and is required to operate within the context of the Bill of Rights enshrined in the Constitution of the Republic of South Africa, 1996. The Bill of Rights affords individual rights to every person and also balances competing rights and communal interests.
- Any limitation of a right must be evaluated and done within a proper human rights based framework and according to the *siracusa* principles; i.e. that the restriction is provided for and carried out in terms of the law, that the objective is legitimate in a democratic society to achieve the desired objective, that there is no less intrusive and restrictive means to achieve the same objective and that in its implementation, the restriction is not intrusive arbitrary or discriminatory
- In the case of **Minister of Health, Western Cape v Goliath and Others 2009 (2) SA 248** where the Cape High Court authorized the forced isolation of four patients infected with extreme drug resistant tuberculosis (hereinafter ‘XDR TB’) at Brooklyn Chest Hospital, DR-TB specialized hospital the case has been declared a bad case and is not followed as a precedent. Respect for fundamental rights in this context [of a perceived trade-off between human rights and public health] will not only ensure fairness towards affected individuals and communities, but will also serve to advance and reinforce public health
- Individual rights should be limited in the interest of public health only when this is the least invasive option available to the State. Moreover, such limitation should only pass muster where public health measures adhere to the principle of legality and are clearly conceptualized, effective, well-targeted, linked to realistic risk-assessment; and applied according to fair and transparent administrative procedures.
- The DOH recognizes that a “fair and standard process must be followed when making the decision to isolate people with confirmed MDR-TB and XDR-TB in order to achieve favourable outcomes. In order to achieve this, the following must be followed:
- Ensure consistency in applying standards across people and not discriminate based on colour, religion and status.
- Engage patients and their families in the decision-making process and they must give consent. All patients must be treated with dignity and respect. Communication must be clear in local language and should be culturally sensitive. There must be transparency, accountability and no hidden agendas. Maintain impartiality and neutrality in the process of decision-making regarding management.

Session II ended at 1519 hrs.

4.4 SESSION III: WAY FORWARD

Session III, mainly discussed key recommendations for responsible government departments and the next immediate steps for commitment by partner organisations.

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Summary of recommendations

1. CHW's, PHO's and provincial administration should be facilitated with capacity building initiatives to equip them adequately to handle TB patients professionally using rights based approaches.
2. The government's budget line for TB which has been the same for the last 10 years should be enhanced to cater for increased needs of TB management and control.
3. TB patients should be fully counselled on the benefits of full adherence to medication and to understand their role in the fight against TB.
4. TB patients should be accompanied by close relatives to hospital to ensure effective communication of prescriptions and adherence.
5. Hospital facilities should be user friendly to the physically and mentally disabled, the blind and deaf who could be suffering from TB, and hospital staff should be trained on appropriate sign language and Braille and attendants should be provided for physically and mentally disabled persons to ensure accessibility and to reduce stigmatisation.
6. Medical practitioners should strive to develop user friendlier medicine for TB that can counteract the side-effects of the current TB drugs to encourage adherence and reduce defaults.
7. Rights should be accompanied with responsibilities. Duty bearers and patients should be properly sensitized on their rights and their corresponding responsibility to respect the rights of others to a clean environment.
8. Patients should be properly sensitised by doctors and PHO's, in a language they understand on the importance of completing their dosage.
9. Patient support in terms of a food basket should be initiated for TB patients during intensive treatment.
10. Prisons should be assisted to develop holding bays for defaulting TB patients pending screening for at least 2 days to avoid spreading TB to other prisoners
11. Isolation units should be established in various possible detention facilities for defaulters depending on their location.
12. Civil society should develop close partnerships with prisons department in order to establish linkages for co-operation.
13. HIV Patients should also be put on TB prophylaxis for 3 years (Isoniazid).
14. Best practices should be documented and made accessible to all.
15. An advisory note should be developed to facilitate the drafting of guidelines and directives on the procedures to be followed by the judiciary before a patient is committed to prison for defaulting on treatment.
16. Healthcare workers should be provided with refresher courses to remind them of their responsibilities in counselling.
17. T.B survivors should be identified and trained as counsellors and peer educators because they are in a better position to effectively counsel.
18. Vigilance should be encouraged with regard to the monitoring of the utilisation of the global fund.
19. KELIN in partnership with AMREF should work to determine the problems bedevilling the proper implementation of the global fund.

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The session ended at 1619hrs with a vote of thanks from Mr. Allan Maleche. He gave an undertaking on behalf of KELIN to develop a workshop report, burn a CD and share the same with participants.



Participants network after the forum

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NATIONAL ADVOCACY FORUM ON THE INCORPORATION OF A RIGHTS BASED APPROACH IN TB CONTROL, MANAGEMENT AND CARE

Date: Thursday, 18th August 2011
Venue: Panafric Hotel Nairobi

PROGRAMME

TIME	SESSION	CHAIR/PRESENTER	OBJECTIVE
8:30 – 9:00 AM	Arrival and Registration		
9:00 – 9:15 AM	Introduction, Welcome Remarks and Objectives of the Forum	Mr. Allan Maleche KELIN	
SESSION 1: EXPERIENCE SHARING CHAIR OF SESSION: Anne Gathumbi Open Society Foundation for Eastern Africa (OSIEA)			
9:15 – 10:00 AM	Video & Testimony Sharing (10min each participant)	<ul style="list-style-type: none"> • TB patients from Kapsabet and Mwea • Health worker - Mwea • Chief - Kapsabet • Magistrate - Kapsabet • Prison Officer – Mwea 	Evaluating key issues from the Community
10:00 – 10:15 AM	Implication of imprisonment and detention of TB patients in the national TB control	Nelson Otwoma (NEPHAK)	
10:15 – 10:35 AM	Key note address: Actualizing the enjoyment of the right to health for TB patients in Kenya, in light of the Constitution.	Mr. Mark Borr Permanent Secretary (Ministry of Public Health and Sanitation)	
10:35 – 10:50 AM	Plenary	ALL	
10:50 – 11:10 AM	TEA BREAK		
SESSION 2: CURRENT STATE OF TB MANAGEMENT CHAIR OF SESSION: Dr. Ibrahim Mohammed (NAS COP)			
11:10 – 11:25 AM	The role of the government in ensuring community and patient participation in National TB programmes.	Dr. Joseph Sitenei Division of Leprosy, TB and Lung Disease (DLTLD)	Interrogating the efficiency in existing provisions and programs, in line with best practices
11:25 – 11:40 AM	Analysis of Global Fund Expenditure in TB Management in Kenya.	Angela Kageni (Aidspan)	
11:40 – 11:55 AM	The Link between TB & human rights in relation to detention of defaulters <ul style="list-style-type: none"> • The South African Experience • The International Standards and Best Practices 	Agnieszka Wlodarski Section 27 & the Stop TB UNAIDS Task Force on TB and Human Rights	
11:55 - 1:00PM	Plenary session		
1:00 – 2:00 PM	LUNCH BREAK		
SESSION 3: WAY FORWARD CHAIR OF SESSION: Lucy Chesire (TB Action Group)			
2:00 – 3:30 PM	Way forward	All participants	Recommendations

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