

# AMPLIFYING VOICES

HEALTH CARE FOR ALL





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HEALTH CARE FOR ALL**

**THE OPEN SOCIETY INITIATIVE  
FOR EASTERN AFRICA (OSIEA)**

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OSIEA supports individuals and groups to participate in matters that affect them and to demand fair treatment, delivery of services and accountability from their leaders, institutions and governments.

OSIEA PLAYS AN ACTIVE ROLE IN ENCOURAGING OPEN, INFORMED DIALOGUE ABOUT ISSUES OF PUBLIC IMPORTANCE IN EASTERN AFRICA.

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# editorial statement

One of the fundamental rights of every human being is to enjoy the highest attainable standard of health. Governments have national and international obligations to provide accessible and affordable quality health care, available to all without discrimination. However, this reality in developing countries such as in East Africa is a distant dream.

The governing principle is that the right to health is subject to the availability of government resources. While governments in this region may be constrained by lack of resources and unable to provide universal health care to the whole population, health services to the poorest and most vulnerable is not a choice but an obligation. Furthermore, governments have a duty to progressively expand the provision of health care each year and the burden is on the government to show that it is doing so and to the maximum of available resources.

The Open Society Initiative for Eastern Africa (OSIEA), in partnership with the Open Society Public Health Program (PHP), works to strengthen the capacity of organizations and leaders in East Africa to advocate for better health policies and practices. We also push for greater government accountability and transparency in health care.

Particular attention is being paid to marginalized communities who are too often stigmatized and criminalized due to their health needs, such as tuberculosis patients who are imprisoned rather than quarantined or HIV positive women who are forcibly sterilized without consent.

Lastly, health rights advocates are acutely aware of the global context which impacts detrimentally in East Africa, including funding cuts to the Global Fund to Fight AIDS, Tuberculosis and Malaria and efforts by western pharmaceutical companies and their governments to block affordable generic medicines by labeling them counterfeit.

This issue contains some of the leading civil society voices in East Africa pioneering innovative and bold health rights work to promote, among other things, access to essential medicines for all, accountability in health care delivery, and to improve end-of-life care for patients with painful terminal illnesses.

OSIEA and PHP are proud to partner and support them in their endeavors.

Binaifer Nowrojee, OSIEA Executive Director



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# Widows' Rights and Inheritance

ALLAN MALECHE

TRADITIONAL JUSTICE MECHANISMS ALL TOO OFTEN DISCRIMINATE AGAINST WOMEN. THE KENYA LEGAL AND ETHICAL ISSUES NETWORK ON HIV&AIDS (KELIN) IS TRANSFORMING TRADITIONAL JUSTICE TO PROMOTE THE LEGAL RIGHTS OF HIV AFFECTED WIDOWS WHO ARE ROUTINELY EVICTED FROM THEIR HOMES BY THEIR IN-LAWS AND THE COMMUNITY

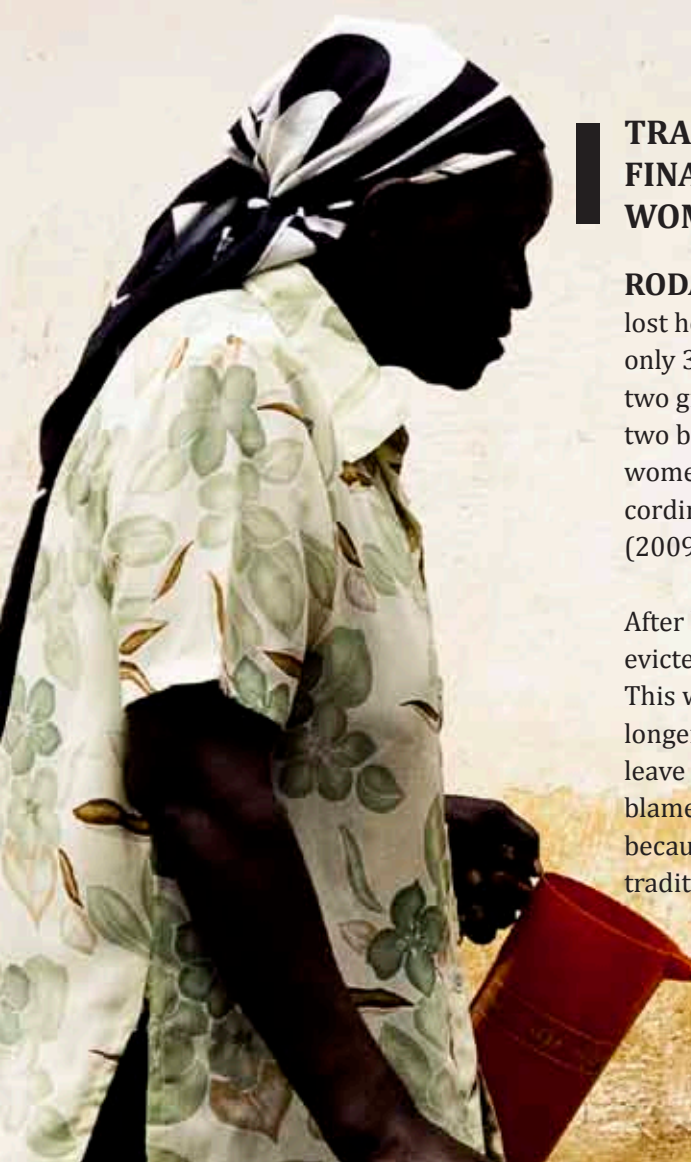
## TRADITIONAL LEADERS FINALLY RECOGNIZE WOMEN'S RIGHTS

**RODAH NAFULA**, a dynamic woman, lost her husband to AIDS when she was only 34-years-old. Rodah was left with two girls and a pregnancy that gave her two boys. Rodah is also one of 760,000 women living with HIV in Kenya according to the UNAIDS Global Estimates (2009).


After her husband's death, her in-laws evicted her and demolished her house. This was to signify that she was no longer part of the family and had to leave their son's home. Rodah's in-laws blame her for the death of their son and because she refused to acquiesce to the tradition of being "inherited" by her

husband's brother. Despite the efforts of a church to intervene by rebuilding a small house, Rodah and her children were not allowed to farm the land or even use the outdoor latrines. "We were forced to go to other homes or wait until night to use the bush" says Rodah.

Rodah's plight is shared by hundreds of other impoverished widows who are denied property rights by their in-laws when their husbands die, especially due to HIV related causes. This disinheritance, often done in the name of culture and tradition, violates women's human rights, depriving them of their homes, their livelihoods, and stability for their children.







Cast out of their homes, many women are forced to seek work in the urban areas where they live in poverty and often resort to commercial sex work. Culture and its discriminatory power leave these women homeless and helpless.

The Kenyan legal system is clear that women and children have the right to inherit and own property under the Constitution of Kenya 2010 and the Law of Succession Act. However, the reality is that the courts are virtually impossible to access for these impoverished rural widows.

Though the traditional justice mechanisms are not a replacement for the formal legal system, this is the forum that rural women most frequently turn to. It is familiar, faster, cheaper and less adversarial as compared to the formal legal system. Affected women seek redress before a panel of community elders who administer customary or traditional law. Generally, these community elders are all male and hold the traditional view that women cannot own land.

This is where the Kenya Legal and Ethical Issues Network on HIV & AIDS (KELIN) comes in to bridge the gap. KELIN has worked for years through a series of community dialogues and human rights

trainings to provide human rights and legal education to the Councils of Elders who administer the traditional dispute resolution mechanism in Kisumu and Homa Bay counties.

KELIN's approach is to partner with and empower the elders and communities they work with using a rights based approach to health. It used to be unheard of that a woman could win a property claim appearing before the Council of Elders. However, with the help of KELIN, 70 women have returned to their homes. Their cases have been successfully arbitrated before the traditional Elder Councils. As of January 2012, KELIN had taken on 114 cases. KELIN has also facilitated the construction of 17 semi-permanent houses for the most vulnerable returning widows. The house building exercise is a community effort that reintegrates the woman and serves as a form of reparations as the community provides the labor and a communal meal.

Rodah is one of the beneficiaries of this project. After participating in a community dialogue forum, Rodah felt that her husband's relatives who had disinherited her would respect the authority of the village elders. She therefore asked KELIN to present her case before the elders and within three months an amicable solution was reached.

Access to justice is central to the principle of equal enjoyment of rights for all in society. Even though traditional dispute resolution mechanisms are now recognized by article 159(c) of the Kenyan Constitution, little or nothing has been done by the government to appreciate their role and value in the protection of rights for women and girls in rural communities.

The success of KELIN has created an increased demand in other ethnic communities to address traditions that breach women's human rights and increase the HIV vulnerability of women. Some of the other practices include female genital mutilation, polygamy and child marriage. KELIN is now scaling up through a working guide for other communities that seek to transform the roles of cultural systems that discriminate against women.

This innovative approach merits consideration as part of a comprehensive rights based response to the injustices that arise from the HIV epidemic in Kenya and elsewhere.

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NETWORK ON HIV&AIDS (KELIN)





AMPLIFYING VOICES 010

# STOP STOCK OUTS

DENIS KIBIRA

STOCK-OUTS OCCUR WHEN PHARMACIES TEMPORARILY LACK MEDICINES FOR DISPENSING TO PATIENTS. THE STOP STOCK-OUTS CAMPAIGN ADVOCATES FOR GREATER AVAILABILITY OF ESSENTIAL MEDICINES IN ALL PUBLIC HEALTH FACILITIES

**UGANDA** is perennially plagued by limited access to medicines, especially in rural government facilities.


The Stop Stock-Outs Campaign is an African regional civil society campaign started in 2009 to combat the lack of essential medicine stocks in government health centers in Kenya, Malawi, Uganda, Zambia, and Zimbabwe.

In Uganda, the campaign aimed to lobby, influence, and pressure the government to make essential medicines available at all times in public health institutions.

The campaign sought to ensure sufficient funding, enhanced transparency in medicines supply management, and a dedicated budget line for essential medicines.

The campaign also advocated for the government to honor the Abuja commitment to spend 15 percent of the national budget on healthcare.

The campaign used various methods to highlight the dilemma of ordinary people who are unable to obtain the medicines they need at the pharmacy near them. The campaign included the formation of a civil



society coalition and partnerships with media, the health ministry, the private sector (through the Medicines Transparency Alliance), members of parliament, and local artists.

Other strategies included regular surveys and “pill checks” at pharmacies to monitor the availability of medicines and their prices. This information was publicly

shared through press conferences, public rallies, radio talk-shows, and community meetings. The campaign raised public awareness about the right to health and access to essential medicines in Uganda as never had been done before, sparking a huge public outcry.

### CAMPAIGN SUCCESSES

Notably, in the first year of the campaign, the Ugandan government responded by streamlining the medicine supply system. The National Medical Stores (NMS) was granted increased financing and operational autonomy. The President and several politicians came out to publicly condemn stock-outs, and the Office of the President created a drug monitoring unit.

Changes in policy and implementation at the Ministry of Health and NMS have tremendously increased the availability of essential medicines in the public sector. In the space of a year and half, there was a 20 percent rise by December 2010 (from 50 to 70 percent) in the availability of 40 essential medicines in the referral public health facilities (health centers IV and above), according to joint surveys conducted by the Ministry of Health, the World Health Organization (WHO), and Health Promotion and Social Development (HEPS Uganda).

Other notable achievements included the doubling of the budget allocation for medicines by the government. The figure went from approximately US\$ 40 million to US\$ 82 million [UShs 101 billion to 204 billion] in the 2010/11 financial year, with rising commitments over the next three years to approximately US\$ 113 million [UShs 281 billion].

Furthermore, the Public Procurement and Disposal of Assets Act (PPDA), which has for several years been blamed for delays in the procurement of medicines, was amended to accord special provision for medicines. This will greatly reduce the amount of time taken to procure medicines.

In addition, NMS instituted changes to improve service delivery. These include the doubling of working hours for their workers, delivery to all health facilities (termed the “last mile delivery”), toll free customer care lines, and seven regional offices. Similarly, the Ministry of Health has received donor support to strengthen pharmaceutical management capacities at health facilities that result from inadequate capacity in forecasting and quantification of medicine needs.

Despite these successes, access still remains a challenge. Unpredictable and fluctuating availability of medicines at public health facilities, coupled with errant prices in the private sector, has made universal access to medicines remain a dream. Availability of key medicines for children has frequently been found wanting. Worse still, medicines for prevention of mother to child transmission of HIV are not readily available in facilities accredited to provide anti-retroviral treatment, and treatment for major infections like pneumonia has constantly been found in less than 50 percent of public health facilities. Furthermore, there is increasing concern over the limited supply of medicines for non-communicable diseases, including cancer, diabetes, and hypertension. Finally, the country is experiencing an acute shortage of health workers, coupled with challenges of inadequate infrastructure and utilities at the health centers.

Alternative health financing mechanisms are urgently required if universal access is to be realized. Moreover, community members need to understand their rights in order to hold the government and other duty bearers accountable. We need to invest in sufficient and motivated health workers and provide them with the tools they need to accomplish their work.

DENIS KIBIRA IS THE NATIONAL COORDINATOR FOR THE STOP STOCK-OUTS CAMPAIGN IN UGANDA

THE CAMPAIGN IS LED BY A CONSORTIUM OF UGANDAN NONGOVERNMENTAL ORGANIZATIONS. GROUPS INCLUDE THE COALITION FOR HEALTH PROMOTION AND SOCIAL DEVELOPMENT (HEPS UGANDA), ACTION GROUP FOR HEALTH, HUMAN RIGHTS AND HIV/AIDS (AGHA), THE NATIONAL FORUM OF PEOPLE LIVING WITH HIV/AIDS IN UGANDA (NAFOPHANU), THE NATIONAL COMMUNITY OF WOMEN LIVING WITH HIV/AIDS (NACWOLA), THE ALLIANCE FOR INTEGRATED DEVELOPMENT AND EMPOWERMENT (AIDE), AND THE UGANDA NATIONAL HEALTH USERS/CONSUMERS ORGANISATION (UNHCO), CENTRE FOR PARTICIPATORY RESEARCH AND DEVELOPMENT (CEPARD) AND THE CENTRE FOR HEALTH HUMAN RIGHTS AND DEVELOPMENT (CEHURD).

DATA CITED IN THIS ARTICLE IS FROM THE MOH/WHO/HAI (HEPS) MEDICINE PRICE MONITOR (VOLUME 10).



STOP STOCKOUTS

GIT DRUGS

ANTI-FUNGALS

ANTIBIOTICS





# ANTI-COUNTERFEITING LAWS THREATEN AFFORDABLE MEDICINES

GICHINGA NDIRANGU

GENERIC DRUGS BRING DOWN THE COST OF TREATMENT AND SAVE THOUSANDS OF LIVES. HAI AFRICA PROTECTS ACCESS TO AFFORDABLE MEDICINES FOR SERIOUS PUBLIC HEALTH THREATS SUCH AS HIV, TUBERCULOSIS AND MALARIA BY OPPOSING THE PASSAGE OF ANTI-COUNTERFEITING LAWS THAT WOULD BAN GENERIC DRUGS

AMPLIFYING VOICES 014

On an ordinary day in any one of the countries in East Africa, a patient walks into a public health facility in search of treatment for a common ailment like malaria. Once observed by a medical professional, the patient is referred to the pharmacy to collect the prescribed medication.

Sometimes the drugs are unavailable and must be purchased from a private chemist. There may be a chance, however small, that the patient buys medicines of doubtful quality that can pose a risk to health. There is no question that appropriate regulatory measures are critical to safeguard the health of consumers.

However, the approach used in addressing this problem has raised serious health rights concerns - undermining access to affordable medicines under the guise of fighting counterfeits.

The definition of what amounts to counterfeit is governed under the World Trade Organization (WTO) agreement on Trade-related Aspects of Intellectual Property Rights (TRIPS). The WTO saw it fit to restrict counterfeiting to trademark infringement so that things like packaging or labeling of medicines do not mislead consumers.

Today, these measures have now been stretched and distorted to include protection of intellectual property rights that safeguard monopoly manufacture of medicines and seek to lock out competitor manufacturers such as the generic drug companies.









## GENERIC DRUGS AND THE DOHA DECLARATION

A generic drug is a product comparable to the brand listed drug and is therefore safe and effective. Generics are sold at a significantly lower cost than their branded equivalents since the development and testing costs have previously been borne by the brand company. Large pharmaceutical companies often spend millions protecting their patents from generic competition which undercut their profits. Generally, generic drugs are only permitted once the patent of the brand drug has expired.

There is one other notable exception: the Doha Declaration. This landmark declaration transformed the ability of poor and marginalized populations to gain access to life saving medicines by lifting patent restrictions for public health threats such as HIV, tuberculosis and malaria. The large pharmaceutical companies have relentlessly sought to roll back this provision by advocating for anti-counterfeiting laws that would ban generics as “counterfeits.”

## ANTI-COUNTERFEITING LAWS

Developed countries, which manufacture branded medicines, are increasingly bullying poorer countries to enforce higher standards of intellectual property protection under the guise of fighting counterfeits. As a result, legitimate generic medicines mainly sourced from India and other developing countries are threatened. Yet these drugs are responsible for saving the lives of thousands of people who otherwise could not have afforded medication.

This is increasingly happening through the enactment of legislation in Eastern Africa ostensibly to fight counterfeits but in actual sense, to tighten enforcement of intellectual property rights as a step towards banning generic drugs. Kenya enacted such a law in 2008 and the East Africa Community is currently considering a regional law that could supersede existing national laws on anti-counterfeiting.



AMPLIFYING VOICES 017

## BALANCING INTELLECTUAL PROPERTY RIGHTS WITH SAVING LIVES

*medication at an affordable price*

Extending the intellectual property rights agenda to safeguard commercial interests will not fully address legitimate concerns over the quality of medicines. While one cannot begrudge the need for a clear and more effective legal framework in this area, the overriding concern of these laws cannot be to protect the rights of intellectual property holders, which ultimately limits access to more affordable generic medicines.

The problem of poor quality medicines will not be contained by enlarging the application of intellectual property rights in order to erect trade barriers for generic medicines. Instead, regulatory agencies need to be strengthened to effectively oversee the quality, safety and efficacy of medicines on the market.

It is also important to accurately determine the scale of the problem. The problem has been blown out of proportion because there are largely no public-spirited independent agencies that can provide credible, empirical data. At the moment, commercial interests have been advanced to blow up the scale and extent of the problem in order to put governments in a panic.

Another problem is that the high price of medicines has resulted in inequitable access and created room for fraudsters to put dangerous medicines on the market. If we are to sufficiently confront the true scope of the challenge posed by medicines of poor quality, the focus on tightening intellectual property rights protection rather than confronting these systemic challenges is an unnecessary distraction.

Then on an ordinary day in any one of the countries in East Africa, a patient will walk into a public health facility in search of treatment for a common ailment like malaria and immediately receive the necessary medication at an affordable price.

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# TUBERCULOSIS IS NOT A CRIME

ALLAN MALECHE AND ANNE GATHUMBI

THE AIDS LAW PROJECT, THE NATIONAL EMPOWERMENT NETWORK OF PEOPLE LIVING WITH HIV & AIDS, AND THE KENYA LEGAL AND ETHICAL ISSUES NETWORK ON HIV & AIDS ADVOCATE FOR COMMUNITY-BASED CARE AS THE STANDARD FOR TREATING TUBERCULOSIS

**I**n October 2010, the Eldoret High Court in Kenya released two men who were jailed for failure to take their anti-tuberculosis (TB) drugs. The magistrate sentenced the patients to eight months in prison, the time it would take for them to complete treatment. After six weeks, both patients were released from prison thanks to the efforts of three organizations—the Aids Law Project (ALP), the National Empowerment Network of People Living with HIV & AIDS (NEPHAK) and the Kenya Legal and Ethical Issues Network on HIV & AIDS (KELIN). The men successfully completed treatment at home.

The case brought attention to the issue of when, if ever, it is appropriate to involuntarily detain TB patients for failure to take their medication. Kenya's Public Health Act permits a medical officer to obtain a court ruling to isolate and detain a person with an infectious disease when a patient negligently and recklessly exposes others to TB by refusing to take their medication despite having received all necessary information. Although the Public Health Act allows for isolation, it does not specify a prison facility, which ultimately led to the High Court reversal on the grounds that the incarceration of patients is excessive.

AMPLIFYING VOICES 019

## RIGHTS VIOLATIONS OF TB PATIENTS

*community based interventions guided by the right information are powerful*

Home to an estimated 130,000 people living with TB, Kenya has the fifth highest TB burden in Africa and ranks in the top twenty-two countries globally, according to the World Health Organization (Global Tuberculosis Control 2011). Over the past decade, some strides have been made to improve detection and provide treatment: Detection rose from 61 percent in 1995 to 82 percent in 2010; and treatment completion rose from 75 percent in 1995 to 86 percent in 2009.

Notwithstanding the great need, treatment literacy and adherence support continue to be underfunded. The Global Fund to Fight AIDS, Tuberculosis and Malaria has committed over \$US20 million globally over the past decade to support large scale prevention, treatment and care programs against these three diseases. Although the Kenyan government received Global Fund money for communication and social mobilization activities, much of these resources were unspent and were ultimately reprogrammed. On the other hand, growing pressure at the local level to avoid the spread of drug-resistant TB has put significant pressure on health care providers and public health officials to do something—anything—ultimately resulting in human rights violations of TB patients.

The two TB patients were neither the first nor the last to be imprisoned for failing to adhere to their treatment.

Another example is SG, a 53 year-old TB patient, who pled guilty in March 2011 to “willfully exposing and spreading an infectious disease to the community” under the Public Health Act. SG had reportedly defaulted three times on treatment. When SG was interviewed by his lawyers, they found that he did not understand the treatment requirements or the charge to which he pleaded. The patient thought he was pleading guilty to stopping his medication, not for putting others at risk. The public health officer in the area admitted that this provision was used quite often to prosecute similar cases.

In the court proceedings, the option of community-based treatment was not even considered. In all three cases, no evidence was presented to demonstrate that patients were infectious or that less restrictive attempts to deliver treatment had been attempted.

In prison, patients are often placed with other inmates and without proper oversight of their treatment, rendering the detention futile as a preventive public health measure. Overcrowding is a common feature of Kenya’s prisons and the quick spread of TB in poorly ventilated conditions is widely documented.





## NO INFORMATION TO PATIENTS

When interviewed by their lawyers, it became clear that the patients had not been provided with basic information from their health care providers on how TB is spread, the length of treatment, and the necessity of completing the full treatment course. Information that TB stops being infectious twenty-one days after commencement of treatment is also not readily available to the public and causes further stigmatization.

Patients do not understand the charges against them and in all cases were told that pleading guilty would reduce their time in remand. When asked why they did not

adhere to TB treatment, they cited lack of food, the need to travel in search of employment and a lack of knowledge about the importance of adhering to treatment.

The fact that all three patients completed TB treatment in the community after they were released is a testament that community based interventions guided by the right information are a powerful mechanism of promoting patient centered models of TB prevention and treatment.

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AMPLIFYING VOICES 021

# MENTAL HEALTH: INSTITUTIONALIZATION OR INCLUSION

CHERUIYOT HILLARY BIWOTT

THE INTERNATIONAL INSTITUTE FOR LEGISLATIVE AFFAIRS (ILA) IS WORKING TO ENSURE THAT THE RIGHTS OF PEOPLE WITH MENTAL HEALTH PROBLEMS AND INTELLECTUAL DISABILITIES ARE PROTECTED IN THE REVIEW PROCESS FOR A NEW MENTAL HEALTH LAW IN KENYA

**In November 2011, the Kenya National Commission on Human Rights published an audit of the mental health system in Kenya. The report, *Silenced Minds, the Systematic Neglect of the Mental Health System in Kenya*, revealed that the policies and practices of the Kenyan government have greatly marginalized mental health, in effect discriminating against persons with mental health problems. Mental health practices and interventions in Kenya are not evidence-based. National data that analyses the nature and extent of the issue is lacking. Not surprisingly, the audit recommends that the government enhance its efforts to provide mental health services across the country in order to meet its human rights obligations.**

**Kenya's mental health services largely follow an outdated medical model that relies on institutionalization of persons rather than a holistic community care approach that seeks community integration.**



## LEGAL REFORM

*Align Kenya's policies and practices to reflect contemporary thinking in mental health*

After a decade of dithering around a mental health policy that was meant to offer a roadmap for implementation of Kenya's Mental Health Act of 1989, there finally appears to be impetus towards a comprehensive review of both the archaic law and the draft policy framework. The Ministry of Medical Services' Division of Mental Health, psychiatrists' associations, civil society organizations and users of psychiatric services commenced a review process aimed at revising and finalizing the draft law and policy.

The aim of this legal review is to align Kenya's policies and practices with the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) and to better reflect contemporary thinking in mental health. Already, the new Kenyan Constitution (2010) has moved the law closer to the international standards, guaranteeing health-related rights, a key step for the reform of the mental health law.

Article 43 enshrines the "right to the highest attainable standard of health, which includes the right to health care services." This is reinforced by Article 54 which states that a person with any disability is entitled to be treated with dignity and respect; to access integrated educational institutions and facilities, and reasonable access to information.

The mental health policy framework will need to be aligned with these constitutional provisions and ensure that there is a decentralized community-based model that reinforces deinstitutionalization of mental health. Segregating people with mental health problems in institutions is not the solution. The International human rights framework requires people with mental disabilities to be able to participate fully in their communities as equal citizens.

## VISION 2030

The realization of Kenya's Vision 2030 is pegged on the capacity of every citizen to contribute and participate in social, economic and political spheres. However, this cannot be realized if mental health is not guaranteed and well taken care of. Under the goals and strategies for 2012, Vision 2030 appreciates that there is need for improved livelihoods of vulnerable persons at household, community and national levels. It states that empowering people with special needs, including those with mental health issues (18.4 percent), is critical.

## ENSURING A HUMAN RIGHTS APPROACH

However, this situation also presents an opportunity to advocate for a progressive mental health law and policy. There is growing public momentum in Kenya to improve the organization and quality of mental health service delivery, community care, accessibility and engagement of people with mental health problems and their families. In addition to the international and national legal frameworks, a vibrant civil society movement of self-help groups, caregiver groups, and community-based service providers are fully engaged in mental health advocacy.

The debate around the new law and policy has renewed a commitment to embed the necessary rights framework into the debate to ensure that the human rights of people with mental disabilities are protected. Stakeholder engagement has been instrumental in developing a more progressive draft Mental Health Care Bill that is based on a human rights approach. Key among its provisions are the comprehensive rights of persons with mental disabilities; integration of mental health services with primary health care; a community mental health approach and deinstitutionalization, and the prevention of mental illness.

It is time to approach mental health from a community-based holistic point of view where users of mental health services are citizens and rights holders first of all, not 'patients'.



# CAN THE GLOBAL FUND BE SAVED?

SHANNON KOWALSKI  
AND ANNE GATHUMBI

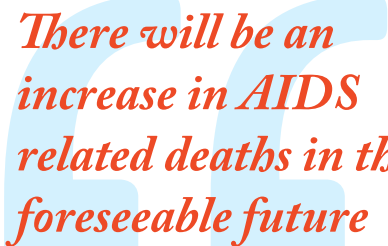
• The Global Fund to Fight AIDS, Tuberculosis and Malaria (Global Fund) is currently in crisis in the advent of major funding cuts by donor governments. The crisis has resulted in the cancellation of an eleventh round of funding and drastic cuts just to maintain funding for essential services.

In ten years, the Global Fund has disbursed some US\$20 billion and saved close to 8 million lives. It has put more than 3.2 million people on HIV treatment and more than 8 million people on tuberculosis (TB) treatment. It has built stronger health systems and civil society advocates to address these illnesses. Its commitment to human rights and marginalized groups

has resulted in policy change and scale up of services for those who would otherwise not receive them. The Global Fund is the largest donor for TB and malaria programs, providing about 70 percent of all external funding, and is the second largest donor for HIV programs.

The crisis comes at a time when evidence in HIV indicates that early commencement of treatment acts as prevention against new infections and can put an “end” to AIDS within reach. The Global Fund is being abandoned precisely at the moment when it can turn the tide on this pandemic.





*There will be an  
increase in AIDS  
related deaths in the  
foreseeable future*

## A LOOMING PUBLIC HEALTH CATASTROPHE

Created in 2002 as a partnership between donors and implementing governments, civil society organizations, private foundations, the public sector and people living with the three diseases, the Global Fund was supposed to be a “war chest,” a well-resourced fund that could rapidly provide large amounts of money to well-performing country-owned programs.

Where do we go from here? No new funding will be considered until at least 2014. In order to find money to cover the already approved 2010 grants, the Global Fund adopted a series of measures to free up funding, including cutting off eligibility to upper middle income countries that are also members of the G20 and do not have severe epidemics. The next round of funding was cancelled, in favor of establishing a transitional funding mechanism to help countries with expiring grants to at least maintain essential treatment services. The crisis is also likely to impact negatively on the massive reform initiative the

## THE GLOBAL FUND IS TOO IMPORTANT TO FAIL

Although the terrible impacts of the funding crisis are yet to be seen, they will be more visible in the next one to two years. In Eastern Africa, most HIV treatment funding is from external sources. Unless East African governments scale up their funding to meet the shortfall from the Global Fund, there will be an increase in AIDS related deaths in the foreseeable future. UNAIDS also predicts a resurgence of TB deaths because antiretroviral medication reduces TB mortality by 60 percent. Given that Kenya, Uganda and Tanzania are among the top 22 countries that bear the highest TB burden, dwindling HIV funding can only escalate the TB-HIV co-infection death rates. Groups most likely to be affected by funding cuts are the

fund had embarked on to mitigate against risk in its grants management.

Some may say that this is a sign of maturity: making difficult decisions in the face of an adverse financial environment and finally recognizing that perpetual growth of the Global Fund is an impossible dream. One can rationalize the decision saying that the Global Fund did not adequately address allegations of corruption or adopt stringent risk reduction strategies. One can argue that this responsibility should fall on developing country governments to increase their own investments in health, take ownership of the AIDS response and better manage their available resources. While all this may be true, this still remains an abdication of donor responsibility.

marginalized populations of drug users, sex workers, prisoners and the gay community whose needs were ignored until the Global Fund made it possible for them to access treatment.

More sustainable and predictable sources of funding for the Global Fund must be found. A financial transaction tax that earmarks funding for the Global Fund is one particularly promising form of innovative financing under discussion at the international level. At the same time countries worst affected by HIV, TB, cancer and malaria need to make lasting commitments to reduce the perennial dependence on external funding.

AMPLIFYING VOICES | 026

TOM ODHIAMBO

# SEX WORKERS AND POLICE DIALOGUE

THROUGH SIMPLE YET EFFECTIVE EFFORTS, KEEPING ALIVE SOCIETIES HOPE (KASH) HAS BUILT A REPUTATION THROUGH AN INNOVATIVE PROGRAM TO REDUCE HUMAN RIGHTS VIOLATIONS AGAINST MALE AND FEMALE SEX WORKERS IN WESTERN KENYA

## BUILDING BRIDGES

Despite the harsh operating environment, KASH has successfully created partnerships to advance the rights of this marginalized population. To date, KASH has helped over 5,000 sex workers and 1,800 men who have sex with men (MSM) to form support groups. By giving them skills in advocacy, human rights, governance, and management, KASH empowers these groups to speak out when they face violence and discrimination.

KASH also promotes the right to health through education on behavior change to avoid or minimize the risks of sexually transmitted diseases. Thanks to KASH, sex workers can now access lubricants and condoms, among other things, in order to stay healthy and reduce HIV prevalence in the course of their work. The Kenyan government also provides health funding through its Total War on AIDS (TOWA) program.



## PROGRESSIVE POLICING

*police officers work with sex workers to enhance personal security and safety*

Police officers in Kisumu are the latest constituency to join forces to ensure the protection of the human rights of sex workers. “We are human beings. We also need your protection just like any other Kenyans,” a male sex worker told police officers during a workshop in Kisumu.

KASH creates spaces for police and sex workers to interact directly about mutual concerns and to jointly identify ways to minimize abuses. Commendably, the Kenya police have acknowledged KASH as a key partner in all police training programs in Kisumu. KASH empowers sex workers as advocates to demand respect and protection from police officers. This has resulted in better collaboration where police officers work with sex workers to enhance personal security and safety. Police in Kisumu have instituted a strong

network that responds quickly to calls of distress from sex workers and the police are at the forefront of facilitating quick access to justice, including the unconditional release of those arbitrarily arrested.

In turn, sex workers often provide police with critical intelligence information gathered from the streets. “Working closely with sex workers has provided the police with a critical population that provides it with information for preventing and dealing with crime in our community. The community policing concept brings in several stakeholders in the society, and sex workers are not an exception. In that respect I strongly believe we are missing our security targets by putting sex workers concerns into jeopardy,” says Chief Inspector Wilson Edung, the head of Kisumu’s police training center.

## SETBACKS

The work is not without challenges. One major issue is the criminalization of sex work under the Kenyan penal code and municipal council laws. Such laws provide openings for police abuse under the guise of enforcing the law. “We have been requested by various leaders of sex workers to directly confront the root cause of their problem by initiating ways through which laws that criminalize their work can be amended,” Velvin Opiyo, a KASH field officer and former sex worker, says. Decriminalization would mean that sex workers could no longer be arrested because of the work that they do (different from the legalization of sex work where the state permits and regulates sex work).

Chief Inspector Edung rightly observes, however, that “sex work is not criminalized in the Kenya constitution. So by working closely with sex workers, the police will not be going against any of its roles as the maintainer of law and order. The police should be properly sensitized on

this during their capacity building trainings and stringent measures should be set out to weed out errant police officers.”

However, his view is not shared by all. The need to institutionalize this new policing approach was starkly highlighted when in 2011 when the area police chief decided to launch a campaign to stamp out prostitution which, according to him, “had led to a high increase in crime,” followed by a sweep of arbitrary arrests by the Kisumu municipal council. KASH is now expanding its trainings to incorporate other security sector actors.

KASH vows to continue advocating with and for these groups to ensure that their rights are not trampled on solely because of their work and that they remain able to access health and other social services as all other members of society.






AMPLIFYING VOICES | 028

# FORCED STERILIZATION IS NEVER THE SOLUTION TO HIV/AIDS







IN KENYA, A COALITION OF WOMEN'S GROUPS WORKS TO EXPOSE FORCED AND COERCED STERILIZATIONS OF WOMEN LIVING WITH HIV AND TO ENSURE THE RIGHT TO REPRODUCTIVE AUTONOMY, INCLUDING THE RIGHT TO BEAR CHILDREN, REGARDLESS OF HIV STATUS

FAITH KASIVA  
CAROLINE OYUGI

**F**illed with the excitement of becoming a mother for the first time, 25-year-old Jane visited an ante-natal clinic for a routine check-up that included an HIV test.

Jane tested positive.

"This was the beginning of the end of my world," Jane agonized. "The nurse told me that I had to do a tubal ligation at the birth of my child because if I had another baby I would die." Jane's husband signed for the procedure on her behalf and against her will.

"Life has never been the same. My husband has had multiple extra marital affairs and has fathered two

more children with two different women. Every time I confront him about his conduct, he says he is looking for more children since I cannot bear him more children."

Ruth, another HIV-positive woman, was sterilized without her knowledge. "They did not consult me about sterilization after recovering [from a caesarian section]. Instead, they told my mother to put her finger prints on paper so that I could go through an operation," said Ruth. Her mother consented thinking she was saving her daughter's life.

Ruth blames the doctor. "Now I cannot give birth again and yet I desire more children," she says. "It is really traumatizing. I wish they had counseled me before doing it."



## DOUBLE STIGMA

There is a long history of such sterilizations of women across the globe, particularly disabled women. Today, it is HIV affected women who are at higher risk of being sterilized without informed consent.

Coerced sterilization occurs when financial or other incentives, misinformation, or intimidation are used to compel an individual. Forced sterilization occurs when a person is sterilized without her knowledge or an opportunity to provide consent.

In most societies, women are most valued for their roles as wives and mothers. Childbearing is central to women's status in the family and community and sterilization has far reaching consequences. Jane observed: "You face stigma as a woman living with HIV/AIDS, but you face double stigma if you are a woman living with HIV/AIDS and sterilized because then you are no longer a woman."



## "AN ACT OF VIOLENCE"

In 2011, the International Federation of Gynecology and Obstetrics (FIGO) released strong guidelines on Female Contraceptive Sterilization. Terming forced sterilization an "act of violence," FIGO has stipulated that only women themselves can consent to their own sterilization. Family members, including husbands and parents, legal guardians, medical practitioners, and public officials, cannot consent on their behalf.

Notably, sterilization to prevent future pregnancy can never justify departure from the principles of free and informed consent nor made a condition of access to medical care or any other benefit. It also cannot be requested when women are vulnerable, such as emerging from labor. Women must be informed in a language they understand that sterilization is a permanent procedure and other contraceptive options explained. Finally, the guidelines recognize the importance of protecting women's access to sterilization when they voluntarily choose this reproductive option.





## KENYAN WOMEN SPEAK OUT

*even HIV-positive  
women have the  
right to have  
children*

Forced or coerced sterilizations are becoming more commonplace in Kenya, capitalizing on the widespread lack of knowledge and poverty. For example, since 2011, a US-based organization called Project Prevention (PP) has encouraged women living with HIV in Western Kenya to opt for sterilization on health grounds and by offering a cash incentive of some \$US 40 [KSh3,200] towards an income generating project after the procedure.

It is against this background that four women's groups namely African Gender and Media Initiatives (GEM), Women Fighting Aids in Kenya (WOFAK), Lean on Me and Grassroots Empowerment Trust documented forty such experiences.

The study found that most HIV positive women are forced or coerced into sterilization when giving birth through caesarean section at healthcare facilities. Some were unaware that they were sterilized until they later attempted to get pregnant.

Although there is no specific legislation, the medical ethics code of practice and the national family planning guidelines for service providers (2010) both underscore the importance of providing full information and obtaining voluntary consent before medical procedures.

The study recommends a review of Kenyan laws and policies that impact on the reproductive health rights of people living with HIV to align them with international standards, including the FIGO guidelines. The report also advocates for greater awareness-raising among women living with HIV, healthcare providers, families, and policy makers. Lastly, there is also need for a complaints mechanism for women discriminated against in a healthcare setting to demand accountability.

"Even HIV-positive women have the right to have children if and when they desire," the Kenyan Minister for Medical Services rightly declared. "HIV doesn't take that right away, not at all." (PlusNews, 2011).

FAITH KASIVA IS THE EXECUTIVE DIRECTOR OF THE AFRICAN GENDER AND MEDIA INITIATIVE (GEM)

CAROLINE OYUGI IS A JOURNALIST WITH AFRICAN WOMAN AND CHILD FEATURE SERVICE (AWCS)

# PALLIATIVE CARE

## LIVING AND DYING WITH DIGNITY

THE AFRICAN PALLIATIVE CARE ASSOCIATION (APCA) SPEARHEADS A RIGHTS-BASED APPROACH FOR PATIENTS WITH LIFE-LIMITING ILLNESSES AT ALL LEVELS OF HEALTH SERVICE DELIVERY

**MARGARET**, a 48 year-old, lay on a mat outside her mother's house in a rural village of south-eastern Uganda. At the age of 35, Margaret was diagnosed with HIV. Her husband of 12 years evicted her. She not only lost her two children, but also her home.

When we visited Margaret, her children and property were the least of her concerns; her feet were swollen and she had developed very painful ulcers. The doctors had just informed her that as a complication of HIV, she had developed a cancer known as Kaposi's sarcoma.

She suffered severe pain. Talking with the community health worker looking after her, she asked: "Do you mean that nothing can be done for the pain I have?"

Morphine is an effective and inexpensive drug of choice for controlling severe pain. However, it is also a legally restricted narcotic which limits its access to people such as Margaret who are living and dying with severe untreated pain.

After Margaret was referred to a hospice program, her physical pain was brought under control. In her last days, she could sit outside the house and laugh with her mother and her community health worker, notwithstanding all the loss she had lived through.

Margaret died eight months later. She was never reunited with her children nor did she know the status of her land. However, thanks to palliative care, she died with dignity, free from debilitating physical pain.

Caring for people with life-limiting illnesses like Margaret is a universal challenge. Whether rich or poor, people who suffer from painful illnesses share common universal needs as human beings. We all need comfort, dignity, love and the knowledge that our loved ones are taken care of.

That is what palliative care ensures.







# Palliative Care is a Human Right

FAITH MWANGI-POWELL, FATIA KIYANGE,  
RACHEL CROSBY AND GRACE MUNENE

**T**he HIV disease burden across sub-Saharan Africa is significant, accounting for 68 percent of the global estimate of 22.9 million people, according to the United Nations Programme on HIV/AIDS (UNAIDS). While anti-retroviral therapy (ART) has emerged as the cornerstone of effective HIV care, it has not negated the need for palliative care for the millions across Africa with such life-limiting illnesses.

There remains a dire need for effective pain and symptom control for the clinical problems that persist for HIV patients including gastrointestinal symptoms, nausea and vomiting, cachexia and anorexia, and chronic diarrhea, as well as psychological symptoms like distress and anxiety.

Despite the need, the current provision of palliative care on the continent is inconsistent, often provided from isolated centers of excellence rather than integrated into mainstream public health systems. Access to culturally appropriate and holistic palliative care is at best limited, and at worst non-existent.

## Palliative care allows people to die with dignity

Cognizant of the discrepancies in the standards of care for people with life-limiting conditions, palliative care providers across the globe have articulated a simple, but challenging proposition: that palliative care is a fundamental human right.

Article 12 of the UN Convention on Social, Economic and Cultural Rights obliges states to provide “the highest attainable standard of physical and mental health” and to “assure to all medical service and medical attention in the event of sickness.”

To clarify and operationalize this provision, the UN Committee on Economic, Social and Cultural Rights, which monitors state compliance, adopted a general comment on the right to health in 2000. According to the Committee, the provision of essential medicines—irrespective of resources—is one of the “core obligations” of governments. The Committee further clarified that states are obliged to “respect the right to health by, inter alia, refraining from denying or limiting equal access for all persons . . . to preventive, curative and palliative health services.” Additionally, the Committee







affirmed the importance of “attention and care for chronically and terminally ill persons, sparing them avoidable pain and enabling them to die with dignity.” (CESCR 22nd session April May 2000 E/C 12/2000/4, paras. 25, 34 and 43).

Despite these clauses, the rights debate is however complex. Although patients and health providers in Africa may have some awareness, they generally have inadequate knowledge of the laws and international standards and little know-how about exactly how to access such services. Additionally, the legal

implications of these issues make judicial officers an important part in addressing human rights issues of palliative care patients and most have little understanding of the issues.

Death is never easy. However, palliative care maximizes the quality of life and relieves the suffering of people to allow them to die with dignity and with peace of mind knowing that their affairs are in order.

THE CO-AUTHORS WORK WITH THE AFRICAN PALLIATIVE CARE ASSOCIATION: FAITH MWANGI-POWELL IS EXECUTIVE DIRECTOR; FATIA KIYANGE, PROGRAMS DIRECTOR; RACHEL CROSBY, PROGRAMS MANAGER; AND GRACE MUNENE, PROGRAMS OFFICER

**DEATH  
IS NEVER  
EASY**

# ENSURING CARE IN HEALTH CARE

ZIPPORAH ALI AND MONICAH MBARU

THE KENYA HOSPICES AND PALLIATIVE CARE ASSOCIATION (KEHPCA) WORKS WITH HOSPICES TO EMPOWER PATIENTS TO KNOW AND DEMAND THEIR PALLIATIVE CARE RIGHTS. PALLIATIVE CARE MAXIMIZES THE QUALITY OF LIFE AND RELIEVES SUFFERING BY PROVIDING CARE AND SUPPORT TO PATIENTS WITH LIFE-LIMITING ILLNESSES AND TO ASSIST FAMILIES TO ADDRESS THE PAIN AND SYMPTOMS AS WELL AS PSYCHOSOCIAL AND SPIRITUAL NEEDS.

Most health practitioners in East Africa do not take time to explain to patients under their care the medical condition facing them. They take it for granted that their patients will not understand what is going on with their bodies and proceed to make decisions on behalf of their patients. Even in cases where patients seek more information, doctors and health care providers do not provide comprehensive explanations that would enable patients or caretakers to make well-informed decisions.

The majority of persons with terminal illnesses are treated in an inhumane and degrading manner at public health facilities, especially in regard to confidentiality of their medical records, information, and diagnosis. Disclosure of personal details is often hurriedly done resulting in misdiagnosis and information being inappropriately shared in public places without regard to the rights and dignity of the person. Patients are also not adequately assessed at the outset, and in many cases the proper diagnosis comes too late. They are denied information about palliative care options and pain management which leads to unbearable and unnecessary suffering and loss of dignity.





Palliative care patients often face complicated legal challenges such as empowering others to make medical decisions on their behalf, writing wills, protecting and disposing of property, planning for children and other dependents, and securing access to health and social benefits. Socially marginalized groups, such as people living with HIV/AIDS, may face discrimination in access to employment, housing, and education due to stigma. Before consenting to participate in clinical trials for therapeutic drugs and vaccines, people with life-limiting illness may require legal advice or information about their rights as trial participants.

In East Africa, partnerships have been developed with lawyers who undergo training on the legal aspects of palliative care before providing pro bono services in hospices. In order to be effective advocates for their patients, hospice and palliative care providers are also educated on a range of legal issues as well as an effective referral network of lawyers and paralegals. This is beginning to change the current situation which usually falls either on a single social worker who is neither legally trained nor empowered to provide legal advice or on lawyers and paralegals with no appreciation of the full range of issues that people with life-limiting illnesses face, including social stigma.

Partnerships between legal advocates and hospice and palliative care providers are thus an effective way to enhance the effectiveness of both sets of professionals, and ultimately to empower patients to demand their rights in order to improve the quality of life.

Palliative care embraces human rights that are already recognized in national and international laws. This includes the right to information about diagnosis, prognosis, and palliative care services and not to face discrimination in the provision of care because of age, gender, national status, or means of infection. Pain relief, access to essential drugs for palliative care, and symptom control for physical and psychological symptoms are also critical. Patients are entitled to family centered care by trained palliative care professionals.

And as the end draws near, patients have the right to receive home-based care when dying as well as to decide whether to have treatment withheld or withdrawn. Lastly, they have the right to die at home if desired. Spiritual and bereavement care are also a part of palliative care as is the right to name a health care proxy for decision making.

ZIPPORAH ALI IS THE EXECUTIVE DIRECTOR OF KENYA HOSPICES AND PALLIATIVE CARE ASSOCIATION (KEHPCA)

MONICAH MBARU IS AN ADVOCATE OF THE HIGH COURT OF KENYA

# IDEALISTIC TO REALISTIC

## Harm Reduction For Drug Users

UMRA OMAR

THE OMARI PROJECT, REACHOUT CENTRE TRUST AND MUSLIMS FOR HUMAN RIGHTS (MUHURI) WORK WITH HEROIN AND OTHER DRUG USERS TO REDUCE HIV TRANSMISSION AND TO SECURE PROTECTION OF THEIR HUMAN RIGHTS THROUGH ACCESS TO JUSTICE AND THE INTRODUCTION OF HARM REDUCTION SERVICES IN KENYA

**MONICA**, a 30-year-old mother of two living in Malindi, Kenya has battled heroin addiction for over a decade. In her own words, “addiction is like trying to resuscitate the body of a loved one inside of you, a sense of loss and desperation with all odds against life—I was dead inside my own self.” Monica has been a recovering heroin addict for more than five years. She has dedicated herself to help others find their way out of drugs.

### ACCESS TO CLEAN NEEDLES

The desperation to “use” once drove Monica to share a needle with other heroin users. She recalls, “the chemists had stopped selling needles to us. I resorted to using one needle over and over again. I tried to sharpen it many times by rubbing it on the concrete pavement when it became blunt. So I just went to my friend’s house because I knew where she hid her needles. I didn’t consider the consequences and so I used it.”

Monica’s friend whose needle she shared was HIV positive.

There are over 49,000 injecting drug users in Kenya with a shocking HIV prevalence rate of 40 percent among this group. Thirty-two percent of injecting drug users are reported to share needles. Less than 15 percent have received any outreach services to assist them (UNODC, *Rapid Situational Assessment of HIV Prevalence and*

*Related Risky Behaviors among Injecting Drug Users in Nairobi and Coast Provinces of Kenya. MARPS Surveillance Report. Nairobi; National AIDS & STI Control Programme—NASCOP (2012)).*

Measures to prevent the spread of HIV, even for those who cannot or will not stop using drugs, is at the forefront of harm reduction. The Kenyan government is in the process of rolling out a needle exchange program, which involves giving injecting drug users clean needles in exchange for their used ones. Studies have shown that access to clean needles plays a strong role in reducing HIV transmission without increasing drug use.

It is critical to curtail the sharing of needles and criminalization of addiction that fuels harm and injustice.



*Access to clean needles  
plays a strong role  
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transmission without  
increasing drug use*

## THE COST OF STIGMA AND CRIMINALIZATION

Along the Kenyan coastal region, many find their way into drugs and have little or no hope of recovering. Stigma, according to Monica, is the biggest impediment facing drug addicts in taking steps to protect their health. The final death blow to their efforts is dealt by the criminalization of this habit.

“Addicts are afraid to go to the hospital,” explains Monica. “They are usually not attended to. Many have unprotected sex because they are scared that if you demand they wear a condom they will be suspected of having AIDS. Young

women are violently chased out of these homes ending up on the merciless streets of this town. You name it, no one wants to be associated with drug users—the option is a silent death.”

It is evident through these experiences that efforts that merely urge addicts to just discontinue the use of drugs do not address the real challenges of addiction. For those that are unable to stop, it is paramount to humanely diminish the harm that they are exposed to, especially the risk of HIV infection.

## LEGAL SERVICES AND HARM REDUCTION

More than 70 percent of the prisoners crowding the cells along the coast of Kenya are convicted on drug-related charges, according to a warden at Shimo la Tewa prison in Mombasa. Many of these prisoners had little or no legal representation and were charged with petty offences.

In 2011, 80 year-old Mohamed was arrested on charges of heroin possession. Shuffled between remand, prison and the courtroom as he waited to begin his ten-year jail sentence, Mohammed despaired. This changed when he met representatives from the community based organization The Omari Project at the end of 2011. With their assistance, he was released under probation.

The Omari Project addresses human rights violations that drug users face both from the police and community. It is through this program that people like Monica and Mohammed have received legal assistance to ensure that justice prevails in the face of stigma and marginalization.

Additional partners include the Reachout Centre Trust and Muslims for Human Rights (MUHURI), whose collaboration with the harm reduction program entails advocacy with key state agencies, including the National Campaign against Drug Abuse, the Ministry of Health, and the Prisons Services.

Drug use and addiction cannot be solved through criminalization and stigma. What is crucial is a two-pronged policy and community approach that reduces further harm to drug users and improves access to justice.

UMRA OMAR IS THE HEALTH AND RIGHTS PROGRAM ASSISTANT  
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# ADVANCING PUBLIC HEALTH THROUGH LITIGATION

ANNE GATHUMBI

ONE OF THE CHALLENGES TO PUBLIC HEALTH IN THE ERA OF HIV/AIDS IS THE CRIMINALIZATION OF CERTAIN POPULATIONS, NAMELY SEX WORKERS, PEOPLE LIVING WITH HIV, INJECTING DRUG USERS, AND LESBIAN, GAY, TRANSGENDER, BISEXUAL, AND INTERSEX (LGBTI) PERSONS

TO MITIGATE THIS DISCRIMINATION, HEALTH RIGHTS ORGANIZATIONS IN EAST AFRICA ARE USING STRATEGIC LITIGATION TO ADVANCE RIGHTS AND SAFEGUARD THE HEALTH OF THE MOST MARGINALIZED POPULATIONS

**S**trategic litigation can be a powerful tool to bring about change for marginalized populations. In East Africa, the courtroom has become a place to oppose the criminalization of HIV transmission,

to counteract homophobia against sexual minorities, to challenge unlawful incarceration of tuberculosis (TB) patients, to demand constitutional guarantees for transgender and intersex persons, and to promote access to essential medicines.

## OPPOSING CRIMINALIZATION OF HIV TRANSMISSION

Although Kenya enacted HIV legislation in 2006, it only came into effect in 2009 after the AIDS Law Project (ALP) filed a lawsuit to compel the government to make the law operational. The case succeeded, but the court unfortunately declined to suspend the offending provisions that criminalized HIV transmission pending the full hearing of the case.

Criminalization of HIV transmission deters people from getting tested to know their status and penalizes women for passing the virus to their children. Fortunately, an amendment to the law has been proposed as part of the law reform effort underway since the passage of the 2010 constitution.





## PROTECTION OF SEXUAL MINORITIES

*Litigation has  
empowered  
marginalized  
groups*

In another groundbreaking case, the Kenyan High Court awarded compensation to Caleb Musaya, an intersex inmate who had been subjected to sexual assault when placed in the male section of Nairobi's maximum security prison. However, the court ruling stopped short of granting legal recognition of intersex persons as a third gender. Like other sexual minorities in East Africa, intersex persons suffer a slew of rights violations often entrenched in laws as well as negative public perceptions.

In Uganda, the Constitutional Court heard a challenge to the Equal Opportunities Commission Act. Established in 2007, the Commission's mandate is to eliminate discrimination

on the grounds of sex, age, race, color, ethnic origin, tribe, birth, creed or religion, health status, social or economic standing, political opinion, or disability. Despite this, the commission is barred from redressing discrimination "involving behavior which is considered to be immoral and socially harmful or unacceptable to the majority." The Parliamentary Hansard (December 12, 2006) shows the provision was inserted because of "homosexuals and the like." This provision was challenged for being unconstitutional and discriminating against minorities. The Attorney General argued that such laws are necessary and justified under the constitution. As of early 2012, judgment was awaited.

## ENDING UNLAWFUL INCARCERATION

In October 2010, the Kenyan High Court ordered two men released who had been imprisoned for not taking their TB medication. Health rights groups – ALP, the Kenya Ethical and Legal Issues Network (KELIN), and Network of People with HIV – filed an appeal of the conviction. In ordering their release, the High Court judgment noted that compliance could

be obtained through less forcible measures. The incarceration was a throwback to the historically coercive model of TB control that violates rights and reinforces stigma rather than a community-care approach that empowers patients and communities through health education and awareness.





AMPLIFYING VOICES 043

## REDRESS FOR MATERNAL MORTALITY

Thousands of women die every year from pregnancy related complications. In East Africa, there is a massive shortage of trained health workers to attend births and to administer emergency obstetric care. To address these preventable deaths, a case was filed in Uganda's Constitutional Court by the Centre for Health, Human Rights and Development (CEHURD) in coalition with 30 other groups. CEHURD charged the government for failing to provide basic maternal services and asked the court to compel compensation to families of mothers who died during childbirth due to negligence and non-provision of maternal health care. The government claimed that the petition was without merit and should be dismissed. As of early 2012, the hearing continued.

These cases illustrate that strategic litigation can bring change, even where cases have not been concluded or the judgments do not resolve the problem fully. Litigation has empowered marginalized groups through their collective power, brought injustices into the public limelight, and upheld constitutional and human rights protections.

ANNE GATHUMBI IS THE HEALTH AND RIGHTS PROGRAM MANAGER AT THE OPEN SOCIETY INITIATIVE FOR EASTERN AFRICA (OSIEA)

# EPAs AND ACCESS TO ESSENTIAL MEDICINES

VICTOR NDUHIU

CIVIL SOCIETY GROUPS IN KENYA HAVE MOUNTED A SPIRITED ATTEMPT TO BLOCK THE EUROPEAN UNION FROM INTRODUCING AN ECONOMIC PARTNERSHIP AGREEMENT (EPAs) THAT WOULD BLOCK ACCESS TO GENERIC LIFE-SAVING MEDICINES. THIS WOULD MEAN A DEATH SENTENCE FOR THOUSANDS LIVING IN POVERTY WHO FACE LIFE-THREATENING CONDITIONS LIKE HIV/AIDS, TUBERCULOSIS AND MALARIA.

## TRADING AWAY LIVES

It has been a decade since World Trade Organization (WTO) member states adopted the Doha Declaration. The landmark declaration transformed the ability of poor and marginalized populations to gain access to life saving medicines by lifting patent restrictions to allow for the production of cheaper generic medicines for public health threats such as HIV, tuberculosis (TB) and malaria. European pharmaceutical

companies and their governments have relentlessly sought to roll back this provision by advocating for free trade and economic partnership agreements (EPAs) with developing countries. While acknowledging the valuable role of intellectual property protection for the development of new medicines, the Doha Declaration commendably puts people before profits, recognizing the need to protect access to essential medicines to promote public health.

*East African countries must not trade away the health of their citizens*



## FREE TRADE AGREEMENTS BLOCK MEDICINES

FTAs, also known as Free Trade Agreements, are negotiated between the European Union (EU) on the one hand, and India and the African, Caribbean and Pacific (ACP) countries on the other. These bilateral agreements negate the gains for health rights made through the Doha Declaration which relaxed aspects of the Trade Related Intellectual Property (TRIPS) agreement for public health crises.

A draft agreement being negotiated between the EU and India would require India to trade away its ability to manufacture generic medicines. Yet India is the pharmacy of the global south saving millions of lives with cheaper generic medicines which form the core of the primary health care systems throughout Africa. India provides about 80 percent of the HIV medicines used to treat more than 6 million people, many of them in Africa, according to the humanitarian organization Médecins Sans Frontières (MSF).

The contentious provisions in the FTA would allow foreign companies to take the Indian government to court over domestic health policies, such as price reductions on medicines. Custom officials will be empowered to seize generic medicines in transit hence preventing them from reaching their destinations. Injunctions by

pharmaceutical companies are also contained in the FTA and are dangerous because they will undermine the independence of the Indian judiciary to protect the right to health of patients over the profits of European drug companies. Other intellectual property enforcement measures, like confiscation of medicines, will put third party treatment providers at risk of police actions and court cases. Provisions on data exclusivity by the originator companies will delay the registration of generic medicines and will not permit affordable versions of pediatric doses and combinations of “off-patent” medicines on the market.

Another contentious clause is the patent term extension which seeks to extend patent life beyond the 20 years that is provided under the TRIPS agreement and the Doha Declaration. Calls by the United States and the EU for greater enforcement of patent rights in determining the price of essential medicines would have devastating consequences on treatment of HIV, cancer, TB, heart diseases, mental illnesses, and many other illnesses.

VICTOR NDUHIU IS AN ADVOCATE WITH THE FIRM OF NJUGUNA KIMANI NDUHIU & CO. ADVOCATES AND A PARTY IN THE CONSTITUTIONAL CASE THAT HAS BEEN FILED

# COMMUNITIES DEMAND BETTER HEALTH CARE

CHRISTINE MUNDURU AND VINAY VISWANATHA

UGANDAN VILLAGERS ARE TRACKING THE HEALTH CARE THEY RECEIVE AND BEGINNING TO ASK FOR MORE WITH THE HELP OF THE UGANDA NATIONAL HEALTH CONSUMERS' ORGANIZATION (UNHCO) AND THE ACTION GROUP FOR HEALTH, HUMAN RIGHTS AND HIV/AIDS (AGHA)

**C**ommunities are often seen as passive consumers of government services rather than engaged participants. The public rarely has a say in the type and quality of health care services being delivered by the government.

In Uganda, community structures such as community health workers (CHWs), village health teams (VHTs) and health unit management committees (HUMCs) have existed for a long time. One could argue that through such local structures the community is provided with a formal space to engage in healthcare decisions. However, the reality is far from this.

## LOCAL HEALTH CARE STRUCTURES FAILING

Although community structures are set up to empower communities to engage in planning and implementation of their healthcare, in reality they merely augment human resources due to the lack of adequate healthcare workers on the ground. For example, VHTs are principally used as primary health centers in Uganda, providing no more than rudimentary health information, dispensing basic drugs such as anti-malarial tablets, referring patients to health facilities, and collecting community health data.

In many places these structures are either non-existent or non-functional. For example, VHTs have been included in Uganda's Health Sector Strategic Plan since 2001; but to date only 55 percent of districts report the existence of VHTs.

An added concern is that most of them are plagued by lack of training, poor supervision, lack of motivation, and poor support structures, especially the replenishment of drugs to be distributed.

Moreover, these services are not rights-based. Education and awareness of the rights of communities about the quality of health care they are entitled to receive are completely missing. As a result, communities can neither participate meaningfully in planning their health services nor can they hold duty bearers accountable when they fall short on the job. Despite the government rhetoric that endorses community involvement, communities often lack the skills and confidence to insert their voices into the delivery of health care.







*Communities often lack the skills and confidence to insert their voices into the delivery of health care*

AMPLIFYING VOICES 048

## EMPOWERING COMMUNITIES

Since 2011, an effort is underway in four districts in Uganda to teach communities how to actively participate in the monitoring and improvement of health services.

The Uganda National Health Consumers' Organization (UNHCO) and the Action Group for Health, Human Rights and HIV/AIDS (AGHA) are implementing a health monitoring and accountability project using a community score card to assess the quality of health services against set standards. The community monitors are drawn from the HUMCs,

CHWs, and VHTs, and receive training on health rights, entitlements, their roles and responsibilities, and the quality of health services expected. Simultaneously, health workers and local authorities at the district level are educated to understand and accept the process.

Monitors gather information from the community that they compile into a score card. They then facilitate dialogue between the community, the local authorities, and health service providers and establish targets for fixing the problems identified. After a determined period, the community monitors assess whether the targets are achieved. The monitoring and dialogue process is carried out periodically and in





a regular cyclical fashion. The findings are also used for advocacy at the national level to address systemic issues.

In Oyam and Masaka districts, the lack of health workers was identified as a key challenge. Since then, health workers have been posted to the two health facilities. The monitors also discovered a staff housing compound, partially constructed, but certified as completed. Bringing attention to this fraud resulted in warning letters and follow up. A woman in Pallisa district observed “we are not afraid of health workers anymore and we are speaking freely about our problems with them.” A health worker in Oyam district acknowledged that “communication

between us and the community has greatly improved. They trust us now and they have helped us improve on issues that have been failing us.”

District leaders are also engaged. “The HUMCs play an important role in monitoring quality of health services, but they lack empowerment and training. This project will close the gap and we are very happy about it” reported the district health officer of Oyam district. The resident district commissioner of Masaka district also suggested that the score card findings be publicly discussed at the regular village meetings.

Community empowerment is a long winding path requiring continuous support and commitment and the results cannot be realized in only a year. However, the outpouring of support from communities, policymakers, and health workers is already indicative of potentially positive outcomes.

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