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COPASAH Communiqué

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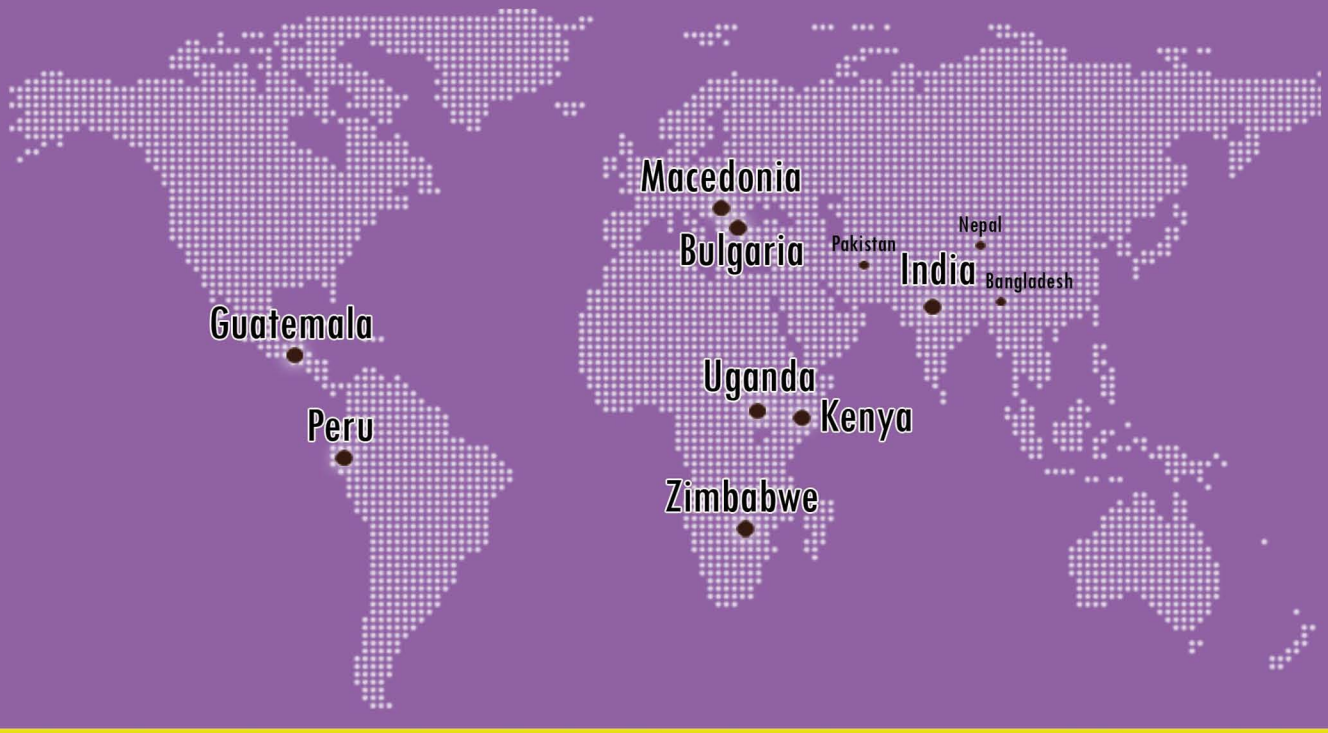

Special Edition on East Southern African Region

Special thanks to Geoffrey Opio (Uganda) and Barbara Kaim (TARSC/EQUINET, Zimbabwe) for coordinating this edition of COPASAH Communiqué

Editorial

Social Accountability in East Southern Africa
Community Action and Empowerment

ABHIJIT DAS

CONTENT

Editorial	01
A Story in Words and Images from Cassa Banana Informal Settlement, Zimbabwe	03
Strengthening Social Accountability through Community Dialogues	06
Intensifying Advocacy for the Legalization of the Right to Health in Uganda	08
Launching of the Uganda Maternal Health Score Card - Towards Transparency and Accountability	10
Mapping Social Accountability in East South Africa: Independent Research Collaboration with COPASAH	13
COPASAH at the Learning Exchange...	14
Our Bodies, Our Lives ...	16
COPASAH Repository of Case Stories from the ESA region	30

This issue of COPASAH Communique has an exclusive focus on the practice of Social Accountability in Sub Saharan Africa. You will read of different initiatives primarily from Uganda and from Zimbabwe. They highlight different arenas of action – from the settlement community to the Parliament, and different methods through which citizen's interact with their health service providers and policy makers including the use of more well-known methods like Score Cards and Participatory Action Research (PAR) and the use of emerging methods like photo-documentation. As practitioners we are all certain that citizen feedback on programming is essential to increase ownership as well as utilisation of health services. Social accountability practices have been known to show that they bring the users and providers closer together to plan and implement better services. In addition these practices build a sense of autonomy and empowerment within otherwise poor and disempowered communities.

However this belief in the need for empowerment as an independent spaces. In such spaces the ideas of aid-effectiveness and efficiency are more favoured outcomes. Take for example the development of the Uganda Maternal Health Score Card process that is described in this issue. It includes development of indicators based on community score cards which will be later converted into dashboards. In the Uganda experience the preparation and sharing of the score card included a multi-level process including the community. However I have also been present in processes where the data for such scorecards is often drawn from official data and such dashboards are more at the national aggregate level. Here the community voice is not truly represented at the table both in any substantive manner, which the method of 'score-card' provides some degree of validity to this exercise as an exercise of social accountability. Such processes can become 'management tools' for improving programme performance, which is a welcome goal in itself, but cannot be said to fulfill the objectives of 'social accountability'.

Community engagement and empowerment need to be seen as

especially in poorly governed areas can lead to some community dissent with existing governance mechanisms and the people concerned. Some donors are reluctant to get into such 'controversial' areas as donors often depend upon official endorsements to fund such processes. Many of the smaller exercises of social accountability that we have been highlighting through COPASAH communiqué often create some local ferment. However at present are there enough means and measures to sufficiently capture 'empowerment' to the satisfaction of the 'gurus' who determine effectiveness particular intervention. Empowerment in many ways is a political process of consciousness which allows critical reflection and action. The experience from Cassa Banana, in Zimbabwe describes the use of photography by community representative to document and reflect upon reality. Increasingly we may need to move to methods which provide more and more control to communities to define their own priorities.

Through the COPASAH Communiqué we have been trying to build up a repository of diverse practice from across different region. We are moving towards creating a compendium of such practices to support the process of mutual learning. We will continue the regional focus that we have started through this issue to highlight the diversity of initiatives from different regions. I do hope you have found the experiences interesting and insightful and we look forward to receiving both feedback and contributions from you.

About the Author

Abhijit Das, Director - Centre for Health and Social Justice (CHSJ), Delhi, India is one of the co-initiators of the idea of COPASAH. Currently he is the global convener of COPASAH. The global secretariat of COPASAH is now housed at CHSJ, Delhi (India), which is one of the pioneering organisations in the field of social accountability in health and community monitoring in South Asia. (www.chsj.org, www.copasah.net)

COPASAH Organised Session in the 4th Global Symposium On Health System Research, Vancouver 14-18 November, 2016

Selected abstract for the organised session:

COPASAH as a global collaborative partnership of public health accountability practitioners for engaging with and health system for increasing access to health services

Abhijit Das [1], Jonathan Fox [2], Geoffrey Opio [3], Renu Khanna [4], Borjan Pavlovski [5]
Centre or Health and Social Justice/COPASAH [1], School of International Service, American University, Washington [2], GOAL Uganda [3], SAHAJ, India [4], Association for emancipation, solidarity and equality of women – ESE Macedonia [5]

Overview: Social Accountability (SA) practices have often emerged from field innovations. Critical challenge faced, however,is knowledge translation and capacity building of practitioners for sustained change. COPASAH, a global collaborative platform of SA , describes *strategies of building -stakeholder platform* and *'how-to' of influencing health system* for sustaining positive changes.

A Story in Words and Images from Cassa Banana Informal Settlement, Zimbabwe

TARSC, ZIMBABWE, CBCHC AND COMMUNITY PHOTOGRAPHERS

Background

In the earlier issues of COPASAH Communique, the Training and Research Support Centre (TARSC) and Zimbabwe Association of Doctors for Human Rights (ZADHR) reported on how Participatory Action Research (PAR) was used in the Cassa Banana community to explore, analyze and take action on priority health problems faced by the community. PAR activities led to the formation of a Community Health Committee (CHC) and the development of a community action plan that prioritized lack of clean water and poor sanitation as the key health problem in the area. Initially, the CHC focused on clarifying the confusion in roles and responsibilities between two district councils, both of whom denied responsibility for supporting Cassa Banana. More recently, the CHC has focused on organizing community actions and engaging with the relevant duty bearer in demanding the delivery of basic services, including access to health services, waste collection, and the improvement of sewage and water supplies.

Cassa Banana is one of many informal settlements that have sprung up around Harare, the capital of Zimbabwe, over the last 20 years or more. In most cases, these unplanned urban settlements are overcrowded, lacking in basic infrastructure and services, with poor environmental conditions for health. Residents are facing a range of other social and economic challenges

Keeping our community clean

common throughout the country, including rising urban poverty, falling access to improved water and sanitation, and lack of overall growth in the economy, employment or household incomes post 2013 (TARSC and MoHCC Zimbabwe Equity Watch 2014). The current Public Health Act has provisions for addressing water and sanitation but these are poorly implemented with an underfunded public health system. Diarrhoea, intestinal infections and periodic outbreaks of cholera are not unusual in settlements such as Cassa Banana.

Despite these challenges, there are opportunities for health and social accountability. The right to health care, water, food and shelter was included in the new Constitution of 2013. Zimbabwe has seen improvements in the Human Development Index mainly due to better health and HIV outcomes, as there is sustained gender parity in education. Improvements in health and wellbeing in Zimbabwe depend, among other things on engaging with the strong social assets within and improving dialogue between communities, state and private sector, in raising and addressing barriers to resources and services for health, and in supporting community efforts to define and act on problems in order to transform their own environments.

Within this context, the work in Cassa Banana is building a body of knowledge on strategies to support community efforts to take action and on how to hold duty bearers accountable. As part of this process, in October 2015, nine community members were trained as community photographers using a PAR tool called Photovoice.

The photographers took hundreds of photographs reflecting the lives and struggles in their community. They then self-edited the photographs to be included it in a 12-page advocacy booklet that described their community. It showcases challenges in the community and the community's response to it. The treatise ends with a request for support from the public and private sectors.

Over the last few months, the booklet has been distributed to many public and private partners. It is too early to assess the success of the booklet in garnering support for Cassa Banana, but it is already evident that the very process of taking the photos capturing the many lives of the community has generated an interest in exploring a number of questions related to the use of Photovoice as a medium of advocacy. Some of the questions include are: Has the process of taking and using the photos deepened understanding of underlying conditions at community level? Has it changed relations and/or levels of organizing between community members (both photographers and non-photographers)? And what impact has use of the booklet had in facilitating changes in interactions with duty bearers? Cassa Banana and partners will be reflecting on these questions in the coming months. Discussions will deepen our collective understanding of the potential of Photovoice as a tool for change.

Cassa Banana Case study reflecting community engagement through photostories as developed by community photographers.

INTRODUCING CASSA BANANA

Produced by the Cassa Banana Community Health Committee and Community Photographers

Cassa Banana is an informal settlement situated about 28 kms from Harare, with a population of about 850 people. The photograph below was taken from the roof of our communal ablution block. It shows how residents in our community live in one or two-roomed wooden cabins. We pay USD 17.00 a month per room to the Harare City Council (HCC). This covers the rent, water and sewage rates, but not all of us can afford to pay the City Council fee.

Most of the residents in Cassa Banana are unemployed. We live by growing food, selling fish which we get from Lake Chivero a few kilometres away, providing services such as hairdressing or carpentry, or through selling vegetables, meat and other goods we get from town. Some of us also manage to find part-time work in the surrounding farms.

An aerial view of Cassa Banana

© L. Dhumukwa 2015

Men catch fish and women prepare the fish for domestic consumption or for selling © M. Mharadze 2015

The water and sanitation crisis is our top priority in Cassa Banana. We have serious problems with burst water pipes and a blocked sewage system. Most of our municipal water taps have not been properly repaired or replaced in a long time so we now only have five working water taps for 850 people. And sometimes the sewage seeps into our water supply through the broken water pipes. As a result, the sewage is polluting our drinking water.

We are trying to keep our communal toilets and surrounding areas clean but this is difficult when the toilet flushing system is not working well due to corroded piping, we have no cleaning materials and no metal bins to throw away our rubbish. The council trucks used to come to Cassa Banana once a week to collect our rubbish, but they haven't come now for many years. So, we dig communal rubbish pits, but these fill very quickly.

In such an environment, it is not surprising that we have related health problems, such as intestinal parasites and diarrhea.

So, what are we doing about this situation?

For many years, we have been fixing our water leaks, clearing out our overflowing sewage tanks, cleaning our ablution blocks, digging rubbish pits, and organizing community cleanup campaigns. The CHC developed an Action Plan in 2014 and this has helped prioritize our work. We hold regular community meetings and, because the nearest public health clinic is 20kms away, we have strengthened our relationship with a private health clinic close by. This year they provided us with deworming tablets.

We are in contact with the Harare City Council and they are aware of our problems. The council members mentioned their challenges of keeping up with the overall situation in Greater Harare, but nonetheless have assured the community of providing labour and technical knowhow if we can supply the plumbing materials. This goes against the constitutional obligations of the Government in providing the basic essentials to the citizens. One wonders at the financial accountability of the government as we are unsure where the 17 USD per month rent from every household that is collected goes.

At the end of 2015, the CHC members and community photographers came together to discuss our plans for the coming year. We decided to continue to organizing ourselves and do whatever it takes to improve our environment. At the same time, we need to continue engaging with the Harare City Council in demanding that they provide health and other services as is our constitutional right. It is also important that we develop new partnerships that help us network with other communities and organizations in getting our health and other basic rights met; to share our experiences and learning with others, and to learn from them.

We are proud of the photos we took last year and are happy with the advocacy booklet we produced. There is still more to do, and many other ways that we can use these photos. We understand that the photographs alone do not create the change we want. These images will be used as evidence for the change that is needed.

All photos are copyrighted to the Cassa Banana Community Photographers: Leeroy Dhumukwa, Paradzai Dimingo, Dephine Hondongwa, Misheck Mharadze, Martin Musodza, Mitchell Ncube, Talkmore Rwanyanya, Pamela Wachipa and Ruth Waeni.

About Authors

This article is based on an advocacy booklet produced in November 2015. It was written by the Cassa Banana Community Health Committee, with support from Barbara Kaim, Training and Research Support Centre (TARSC) Zimbabwe. TARSC is a learning and knowledge organisation, with a strategic vision to inform and contribute to people and social justice change and to support sustained health and wellbeing. See www.tarsc.org for more information or admin@tarsc.org .

For more information about how PAR and Photovoice have been used in Cassa Banana, see
http://www.equinetafrica.org/sites/default/files/uploads/documents/EQPRA%20Cassa%20Banana%20April%202016.pdf

Strengthening Social Accountability through Community Dialogues

Engagement initiative to Stop Medicine Stock Outs (COME) that aims to fostering action, engagement and participation of the community.

JOAN KILANDE AND ERIC WAKABI

The Coalition for Health Promotion and Social Development (HEPS UGANDA) Uganda is successful in implementing the Citizen's Engagement initiative to Stop Medicine Stock Outs (COME) that aims to fostering action, engagement and participation of the community. This initiative which was kick started in March 2014 has today shown that the community engagement can increase social accountability. Community leaders are forging a path towards advocacy of health rights for all. This includes ensuring every citizen has access to essential medicines in every public health facility, where the availability of essential drugs is adequately provided and above all health care services are improved to serve the community.

A woman drops a suggestion in the suggestion box that was provided during the implementation of the community action plan. This resulted in community dialogues and interface meetings at Katwe HCIII, Dwaniro Sub County, Kiboga District.

The focus of the initiative was to get the public health facilities in Lira and Kiboga districts up to health care standards. Citizen Report Card (CRC), a social accountability tool was used to provide feedback received from the users of public services to the public health agency. The feedback was received through the sample surveys that were conducted on different aspects of service quality. This enabled the public agencies to identify strength and weaknesses in their work. The CRC was further used to identify key gaps, with a way-forward, a plan to fix the gaps that came up during the discussions between the community, service providers and duty bearer.

The Uganda Government recognizes the importance of community involvement in the successful fulfillment of the right to health. The National Development Plan (NDP), the overall Government development strategy, sets and prioritizes the empowerment of individuals and communities for a more active role in health development and the implementation of the Uganda National Minimum Health Care Package (UNMHCP).

During the project life-cycle, it was heartening to see collective action at work, especially when a community gets together to demand for their entitlements. Such is the chronicle of the residents of Dwaniro Sub County, Kiboga District, who observed that a lack of adequate and standard infrastructure compelled them to lobby for a positive change in the status of their health centre, eventually achieving 50% of service enhancement of what was originally targeted.

In Kiboga District, inadequate infrastructure is affecting access to services in all the health facilities. For example, the district hospital is a 100 bed capacity but the intake of patients is over 150 which puts the pressure of hospital management at risk. This means that the current ward capacity which has limited capacity cannot match with the volume of admissions. It is often a common sight to see patients sleeping under beds, or in the veranda. Male and female patients are put-up in the same ward. These are reasons to believe that the health consumers are

shunning away from public health facilities as they lack adequate care. The community work experience in Dwaniro Sub County is an ideal example to showcase how monitoring service delivery can yield positive outcomes through the process of social accountability and community participation. During the interface meetings facilitated by HEPS Uganda between the health workers, community leaders and community members in the last quarter 2014, Katwe community members identified issues that were affecting their health centre and these were prioritized in the community action plan. The health centre lacked a clear complaint and redress mechanism, a placenta pit, and had poor accommodation facilities for staff. The General ward and OPD department were of substandard, a situation that had affected the access to services in this health facility.

The community members of Dwaniro Sub County in collaboration with the health unit management committee members and the health facility in-charge agreed to submit a proposal to the sub county, district headquarters, politicians and development partners to solicit for support to improve the health facility infrastructure. In addition, community fundraising conferences were held to supplement the development works at the health centre.

The district councilor Nelson Agaba, informed community members of Dwaniro Sub County during a quarterly community action plans review meeting that due to the lobbying, the staff quarters were included in the district work plan for the year 2015. In this regard, through community fundraising meetings, the community members also contributed money, bought building materials to help in the construction of the health workers staff houses.

The health centre beefed up its health education programmes to keep to the goal of information dissemination, now to include health rights and responsibilities of clients and the use of rational medicines among others.

In Uganda, the range of health services varies with the level of care in public and private health facilities. Public health facilities up to Health Centre III (HCIII) offer basic services as per the minimum health care package. HCIIIs in particular the lowest facilities accessed at village level render a comprehensive health care package. At HCIIIs there are provisions for laboratory services for diagnosis and it is the first referral cover for the sub county as the third lowest unit of local government. But, access to services in these health facilities is limited due to a number of factors such as sub-standard health care facilities, unavailability of drugs and lack of awareness of community about their rights and standards of service.

Healthcare promotion in Uganda is strongly dependent on availability of adequate infrastructure, facilities, and technology. To a large extent, the infrastructure, equipment, furniture and vehicles define the capacity of a health centre to deliver health services to the population. However the state of the current infrastructure is below the standard of the adequate infrastructure set by the Ministry of Health.

About Authors

Joan Esther Kilande holds a bachelor's degree in Social Sciences and majored in Gender Studies. She has a certificate on Primary Health Care. She has certificates in Reproductive Health and Human Rights, Policy advocacy and Social media campaigns. She has been working with Journalists for the last 5 years in various health and human rights campaigns and has skills and experience in using social accountability approaches specifically the Citizens Report Card (CRC), Community Score Card (CSC) and the HEAR model.

Wakabi Eric is an all-round communication specialist and journalist with more than three years of experience in, health policy advocacy and communicating development issues to various Newspapers, Magazines, and Internet Productions, NGOs in Uganda and South Sudan. He holds a B.A Mass Communication degree of Makerere University and currently pursuing Bachelor of Laws at the same University. He's currently a communications officer at HEPS –UGANDA.

Intensifying Advocacy for the Legalization of the Right to Health in Uganda

MOSES TALIBITA

Uganda National Health Consumers' Organisation (UNHCO) guided by her vision("A Uganda where the healthcare system guarantees full enjoyment of the right to health by all people) and indebted to her mission (to promote full integration and implementation of the rights based approach in Uganda's health sector through meaningful citizen-duty bearer engagement in healthcare planning and delivery)conceived an idea of advocating for the inclusion of the Right to Health in the 1995 Constitution of the Republic of Uganda as amended because the same is not expressly stated in the Constitution.

The right to health is a fundamental part of our human rights and understanding of a life of dignity. The right to enjoyment of the highest attainable standard of the physical and mental health is not a novel idea, it was articulated in the 1946 Constitution of the World health organisation(WHO), whose preamble defines Health as 'a state of complete physical , mental and social well- being and not merely the absence of disease or infirmity.' The preamble makes mention of ' the enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being without distinction of race, religion, political belief, economic or social condition.'

The Universal Declaration of Human Rights is express of Health as privy to the right to an adequate standard of living in Art. 25. In like manner, the 1966 International Covenant on Economic, social and cultural rights identifies with the right to health as well.

Henceforth, other international treaties have recognised or referred to the Right or to elements of it, such as the right to Medical care. The right to health is relevant to all states: every state has ratified at least one international human rights treaty recognising the right to health. Moreover, states have committed themselves to protecting this right through international declarations, domestic legislation and policies and at international forums.

Contemporaneously, increasing attention has been paid to the right to the highest attainable standard of Health, by human rights treaty monitoring bodies, WHO and Human Rights Council, which in 2002 created the mandate of Special Rapporteur on the right of everyone to the highest attainable standard of physical and mental health. The initiatives have helped clarify the nature of the right to health and how it can be achieved.

UNHCO Right to health legalisation approaches

Making legitimate the demand by citizens for the universal enjoyment of health goods and services fell in two fronts for which UNHCO mounted a protracted campaign to realise by July 2015.

- The constitutional inclusion of the right to health that creates claimable health services and goods on the one part
- The Legislative initiatives that legitimises patient's rights and responsibilities.

UNHCO has constructively engaged with stakeholders to advocate for legitimising the right to health in Uganda. The realisation of the right to health has been found to start with the creation of a receptive legal framework, according to the Chairperson of the legal and Parliamentary Affairs Committee of the Parliament of Uganda.

UNHCO worked with key stakeholders through coalitions as a fact-finding strategy on possibilities of gathering arguments to be compiled in affidavits to beef up the evidence for the right to health. UNHCO built partnerships with institutions including the Uganda Human Rights Commission, Uganda Law Reform Commission, and Parliament among others, and formed a Patients' Rights Bill Working Group (Task Force). The working group comprise members with expertise in Human Rights, Law, Health and interpretation of legal documents to which UNHCO benefitted in identifying health rights violations that impend the realisation of the right to health in Uganda.

The legal recognition of the right to health in Uganda has never attracted as much interest. It is beyond challenge that the Constitution does not give claims for entitlements for Health

Responding to Rights Violations

UNHCO responded to cases of health rights violations and highlighted them for action such as the dismissal of pregnant students from university, stating *that the dismissals selectively deny female students to equal opportunities for education enshrined in the Constitution of Uganda as their male counter parts are never affected, hence failing them from benefiting from favorable conditions for education, freely associating with fellow students hence casting a dark cloud on their future which is likened to double jeopardy*.

UNHCO's Patient Complaint forms were also distributed at project target health facilities - these formed a complementary redress mechanism for illegal violations and collect evidence for advocacy for the right to health.

goods and services for Ugandans.

Legitimizing patient's rights and responsibilities – The Patient's Rights and Responsibilities Bill, 2015: Whereas Article 8A(1) provides that the National Objectives and Directive Principles of State Policy are principles of national interest and common good unto which Uganda shall be governed. Legalising the same requires a law making process cum Article 8A (2). Clearly, ensuring basic medical services and access to health services are legally barren.

UNHCO launched a protracted campaign for the legitimization of the Patient's right's charter. Learning from her engagements that ultimately led to the adoption of the patient's charter by the Ministry of Health, UNHCO sensitized Parliamentarians on the advantages of having a law that protects patient's rights. On the 26th of February, Hon. Milton Muwuma sought leave of parliament to draft and later table the Patient's rights and responsibilities Bill, 2015.

Parliament assigned the mover definite time within which he could present the Bill for the first reading. The law required that he obtain a certificate of financial obligation from the Ministry of Finance and economic planning that was expected by September 2015.

This Patients' Rights and Responsibilities Bill makes lawful patients' responsibilities as well, making patients take charge of their health and health workers to respect the patient's rights to treatment, privacy, referral, informed consent and information. This would promote mutual accountability, quality of care and universal health coverage.

Constitutional processes for the right to health

National consultations were conducted with the Ministry of Justice and constitutional affairs, Uganda Human Rights Commission, the Ministry of Health, the Parliament of Uganda and Civil Society Organisations.

UNHCO led civil society to submit a proposal seeking to expand article 22 of the Constitution that protects life to Article 22 A to provide for the right to health. The proposal however never appeared in the government proposals that were brought forth before the legal and Parliamentary Affairs Committee of Parliament.

The clerk to the Legal and parliamentary Affairs committee invited UNHCO to appear and present submissions on the Constitutional (Amendment) Bill No. 11 of 2015. UNHCO joined by other civil society made submissions to the committee of parliament the Right to Health proposal that read as follows:

The 1995 Constitution of the Republic of Uganda's shall read: Article 22 A (1) the state shall take reasonable measures within its available resources

Continued on page 29

Write back to us with your feedback and inputs at copasahnet@gmail.com

Launching of the Uganda Maternal Health Score Card - Towards Transparency and Accountability

AZIZ AGABA

In November 2013, Uganda launched a health care plan- *A Promise Renewed Sharpened and first Integrated Reproductive, Maternal, Newborn and Child Health (RMNCH)* with clear goals, objectives, priorities and implemented five strategic shifts in order to employ new ways of combating RMNCH challenges. The plan aims to accelerate reduction in maternal, newborn and child mortality, to improve Uganda's RMNCH indicators by 2017. Health indicators with respective targets were identified to sharpen the plan. In order to track the progress against the ambitious goals and targets, the government had to invest in efforts to track performance.

Staff and Management Committee of Bigasa HCIII convene to discuss the action plan during the training at the sub-county level in Bukomansimbi District

Therefore, the endeavour of developing and implementing the Uganda RMNCH Scorecard is in line with global initiatives including the A Promise Renewed (APR)[1], UN Commission on Information and Accountability among others. Under the APR initiative, the Ministry of Health progressively institutionalize a national and sub-national RMNCH scorecard based on routine Health Management Information System (HMIS) data and the District Health Information System (DHIS) platform. The Uganda integrated RMNCH proposes a quarterly dashboard monitoring system at the national level to compile data for scorecard in the first month of every quarter. This will also be applied at the district and health facility level. The scorecard is aimed to facilitate health facilities to review their performance within the quality improvement framework.

Based on The African Leaders Malaria Alliance (ALMA) Scorecard for Accountability and Action, the RMNCH scorecard is a mechanism through which decision makers, and other different stakeholders like community leaders, civil society organisations, etc. can track progress on RMNCH performance using metrics at different levels from national, regional, district and sub-district level. The scorecard represents an important tool for identifying locally owned and solutions to RMNCH performance issues. The Scorecard enables an action mechanism and progress tracking to facilitate comparisons across regions, districts and health facilities and to increase transparency and accountability around action. The Scorecard visually highlights specific RMNCH indicators that are doing well and areas experiencing bottlenecks and slower progress. Therefore, Uganda RMNCH scorecard presents an opportunity to:

- Enhance transparency, accountability and action around

[1]A Promise Renewed (APR) brings together governments, civil society, the private sector and individual citizens to stop women and children from dying of causes that are easily avoidable. For more information on APR visit: http://www.apromiserenewed.org/about/

- RMNCH.
- Enable better profiling and monitoring of high-impact RMNCH interventions to help decision-makers identify and prioritise gaps.
- Facilitate and strengthen evidence-based action plans to improve internal management of programmes and policies.
- Serve as an advocacy tool for external partners and civil society organisations.
- Align priorities and actions with existing national review processes and timing.
- Validate and triangulate the implementation of actions intended to improve the health outcomes of women and children.

Piloting the RMNCH Score Card

In order to achieve the desired outcomes like that of ensuring transparency, accountability around RMNCH etc., the RMNCH scorecard was subjected to a pilot exercise and concept demonstration was done in 13 districts i.e. Butambala, Bukomansimbi, Mukono, Tororo, Mbale, Kiboga, Kibale, Bundibugyo, Kabarole, Masaka, Busia, Hoima and Mubende across the different regions of Uganda to test the effectiveness and efficiency of its accountability mechanism.

During the pilot exercise, district teams composed of both technical and political officials including HIMS focal persons, Biostatistician, Records Assistants, and Health Facility In-charges, Community Development Officers among others at district, sub-county and community levels were oriented and trained on the scorecard. The district teams jointly generated multi-level scorecards from district to health centre II levels, drew action plans and assigned roles to appropriate accountability mechanisms. The Proof of Concept Demonstration (PoC) was carried out to test the efficiency and effectiveness of accountability mechanisms in responding to issues identified in the scorecards.

Performance review using the RMNCH scorecard selected accountability mechanisms

Depending on the organization unit or level of performance review, the review and interpretation of the RMNCH scorecard involved both direct and indirect technical personnel, politicians and development partners among others in the district. The process garnered high-level support at all levels. The target audience and platform had the potential to account for RMNCH performance at that level, make or influence decisions and follow up action items prioritized. The categories of the accountability mechanisms included sectoral committees, DHTs, sub-county level committees, HUMCs, community members.

Levels of engagement with accountability mechanisms

The PoC was conducted at three levels (categories) following the local government structure:

- District and Health Sub District
- Sub-county[2]
- Community level

Uganda's Local government structure is hierarchical in nature. It starts from village, parish, sub-county, county and district levels. In the development of the accountability mechanisms for the scorecard, only three levels were considered. Engaging the accountability mechanisms, categories

Org Unit	Reporting Rate	C-Section Rate	Institutional U5 Mortality	Institutional Maternal Mortality	Institutional Newborn Mortality	% Of Babies With Birth Asphyxia	% Of Mothers Initiating Breastfeeding	% Of Sick Neonates Presenting To Health	% Babies Receiving P N C Checks Within A
Abim District	100.0	0.0	116.9▲	0.0	8.1▲	0.81	0.0	0.0	69.0
Adjumani District	100.0▲	9.1	27.1▲	0.0▼	1.7	1.2	0.0	32.0▲	73.9▲
Agago District	100.0	3.8	0.0▼	0.0	0.0	2.0	0.0	80.0▲	23.1
Alebtong District	72.2	1.8	0.0	0.0	0.0	2.6	0.9		46.3▼
Amolatar District	100.0	3.5	0.0	0.0	0.0	0.98	0.0	100.0▲	60.7▼
Amudat District	100.0	2.9	0.0	0.0	0.0	1.2	0.0	100.0	70.3▲
Amuria District	100.0	0.97	0.0	0.0	0.0	3.3	0.0	62.5▼	58.0▼
Amuru District	100.0▲	0.0	0.0	272.5▲	0.0	0.82	8.1▲	42.9▼	38.1
Apac District	97.1▲	5.2	0.0▼	0.0	0.0	7.5	0.0	45.0	70.0▲
Arua District	94.5▼	9.2	0.94	47.1▼	0.0	0.75	0.0	27.6▼	18.1
Budaka District	100.0	0.0	0.0	0.0	0.0	0.36	0.0	50.0▼	22.7▼
Bududa District	100.0	2.5	22.2▲	370.4▲	0.0	0.74	0.0	46.2▲	97.0▲
Bugiri District	98.0	8.4	0.0▼	603.1▲	0.0	5.9	0.0	0.0▼	75.2▲

Screen shot of the district scorecards as generated from the National Health Information System

[2] The administrative divisions of districts in Uganda are further divided into counties and sub-counties. Since 2005, the Ugandan government has been in the process of dividing districts into smaller units, with the most recent change in August 2010. This decentralization is intended to prevent resources from being distributed primarily to chief towns and leaving the remainder of each district neglected.(https://en.wikipedia.org/wiki/Districts_of_Uganda)

were derived as there were limitations of time and there was an assumption that there is consensus amongst different health actors within the same category. District and Health Sub District are largely policy actors, sub-county actors are largely implementers and the communities are the beneficiaries/consumers.

At the sub-county level, the participants noted that enforcement of action plans could be done by ensuring that there exist jointly drawn schedules, duty rosters, monitoring schedules, and involvement of sub-county stakeholders.

While at the district and health sub-district level, regular joint monitoring and supervision was suggested as a key component of enforcing actions generated from the accountability mechanisms. They further noted that training of the HUMCs and the sub-county officials in the use and application of the scorecard would help them to implement the actions by clarifying the systematic processes to undertake to address issues identified.

At the community level, the communities suggested regular information and feedback from the sub-county headquarters and the health centres that serve them.

Launching the RMNCH Score Card at National Level

Following the completion of the PoC, the scorecard was launched on September 3 2015. During the launch, the UNHCO Executive Director, Robinah Kaitiritimba noted that UNHCO was selected to develop the scorecard owing to her previous experience in successfully implementing social accountability programs. She noted that UNHCO has been working with scorecards for quite a while especially at the community level – raising citizen awareness on rights and responsibilities.

"*We are happy to say the (the first phase of the) scorecard process has been completed – we started off about a year ago. We thank World Vision for being the grant holder. Most importantly, we also thank Ministry of Health, UNFPA, UNICEF, WHO and the district stakeholders that have been very helpful – they are very excited about the opportunities and ease of work with data that the score card brings*".

"*We started off with meetings to solicit system needs from various stakeholders. We discussed indicators – some of which are not monitored by the information system at the Ministry developed the indicators, we went back to the drawing board to develop the scorecard*".

"*The team that is here is the one that has been at the centre of the development of the Score card. We appreciate the efforts you have put into its development*".

The development of the scorecard was done in a participatory, inclusive and consultative manner to include the district and national level stakeholders and health development partners. The Ministry of Health expects that the scorecard will galvanise and increase stakeholder collective performance assessment and support for quality RMNCH services for all Ugandans.

All actors (public sector, private sector, civil society development partners and donors) from all levels of policymaking, program management, service provision and community mobilisation were called upon to ensure sustainable access to RMNCH services in Uganda. ■

About the Author

Aziz Agaba is working as a Programme Officer with UNHCO.UNHCO is a membership non-governemental organisation working in Uganda. Since its inception in 1999, UNHCO has been implementing programmes that advocate for a strong institutionalized platform that is able to articulate voices of consumers of health goods and services. UNHCO has championed the Rights Based Approach (RBA) to healthcare delivery and contributed to efforts to improve community participation and accountability. For more information on UNHCO, Pls visit: www.unhco.or.ug

Mapping Social Accountability in East South Africa: Independent Research Collaboration with COPASAH

LUUL BALESTRA

I am an independent researcher with a strong interest for participatory health governance, social accountability and community mobilisation for the right to health care. I came across COPASAH while researching the case of a grassroots women organisation *Mahila Swasthya Adhikar Manch*, or Women's Health Rights Forum, supported by the COPASAH member organisation SAHAYOG) and its struggle to obtain health system accountability through Community Based Monitoring (CBM). As I dug into that experience, I came to deeply appreciate the need for promoting a theoretical and practical debate on social accountability as a political project.

With this in mind, I am now glad to be able to initiate a partnership with COPASAH with the goal to map the field of social accountability in health in the Eastern and Southern Africa region. The number and variety of experiences in the region is huge and a need was felt among COPASAH Steering Group to gain a greater understanding of its present and future of the actual and potential role of the network. The overarching goal, thus, is to expand COPASAH's understanding of the region - including what the main actors, trends, successes, and challenges are - and to provide it with a frame from which to strategically position itself, support practitioners in the field and promote social accountability for inclusive citizenship.

The mapping will be done by interviewing key actors in the field – already involved or not yet in COPASAH's activity so far - identified through snowballing methodology. I will primarily collect data and conduct face to face interviews during field visits to organisations active in part of the region, and secondarily via Skype. The visits and interviews will be carried out between June and September 2016. The output will be a report in co-authorship with COPASAH which will summarize the results of the mapping exercise and possibly include few case studies on the work of selected practitioners in the region.

In addition to this for a more structured part of the research, I would be very pleased to be contacted by any members or readers with an interest in sharing their experience and ideas on social accountability for health in the region. Those with an interest in getting involved can contact me via e-mail at luul.balestra@hotmail.com. I am looking forward to working on this project together collaboratively and contributing to the debate on social accountability for the right to health care. ■

About the Author

Luul Balestra is currently an independent researcher interested in social accountability for the right to health care. She has worked on community mobilisation for health and health care for years, focusing on various issues such as migrants' health, right to food and maternal health among others, and in contexts as different as Italy, Brazil, USA, Pakistan, India, South Sudan, Cameroon and the UK. In her latest role, she managed the community engagement portfolio of Healthwatch, an independent watch-dog for local health services in Central London. She holds a Master's degree in Health Community and Development from the London School of Economics.

COPASAH at the Learning Exchange: Transparency/Accountability Strategies & Reproductive Health Delivery Systems

Accountability Research Centre, School of International Service (American University), Washington DC (June 27-28, 2016)

E. PREMDAS PINTO, RENU KHANA, WALTER FLORES

Participants at the learning exchange meet

A learning exchange on Transparency/Accountability strategies and reproductive health delivery systems at the American University was held on June 27 and 28, 2016. The learning exchange was convened by Accountability Research Center, School of International Service, American University along with the Evidence Project, International Planned Parenthood Federation and Reproductive Health Supplies Coalition, Advocacy and Accountability Working Group. COPASAH was represented at the learning exchange meeting by two Steering Committee members including Walter Flores (CEGSS, Guatemala) and Renu Khanna (SAHAJ,India) - and E. Premdas Pinto from the COPASAH Global Secretariat, Centre for Health and Social Justice(CHSJ, India).

The learning exchange was convened in the background of systemic weaknesses, vulnerabilities and biases which at different points in health systems form bottlenecks for the reproductive health (RH) supplies to reach the last mile. Practitioners, researchers and persons involved in the field of Transparency, Participation and Accountability (TPA) participated in the learning exchange. The goal of this learning exchange was to inform and identify practical strategies to address unidentified and unmeasured bottlenecks in the process of procuring and moving commodities through the supply chain into health facilities at different levels as well as the barriers that impede citizens' enacting of full, free and informed contraceptive choices. One key proposition for discussion was the issue of public monitoring which can inform problem-solving and policy advocacy, while problem-solving or advocacy strategies can in turn inform monitoring strategies.

The objectives of the learning exchange were set as follows:

1. Share analytical insights, key concepts and practical developments from both transparency, participation and accountability and the reproductive health systems, including commodity security;
2. Learn from experiences by addressing issues of supply chain challenges in various sectors ;
3. Identify research gaps and/or questions for addressing the monitoring challenges involved in tracking the determinants of

access to contraceptive services;

4. Contribute to practical research agendas;
5. Discuss possible strategies for improved monitoring through collaboration and sharing between RHSC and TPA sectors.

Presentations:

COPASAH members made presentations on various experiences of practice of citizen empowerment and monitoring.

In the session *'Key concepts and lessons from the emerging field of Transparency, Participation and Accountability'* which was chaired by Kelsey Wright, Evidence Project, E. Premdas Pinto from COPASAH Global Secretariat, CHSJ, made a presentation and shared the experiences of COPASAH strategies of bottom up accountability practice, networking of practitioners, using ICT for networking and advocacy for the citizen centric accountability practice.

This session introduced some key concepts and lessons emerging in the TPA field and used concrete examples of how they have been applied in different sectors and to what effect. This includes approaches to advocacy, problem solving and policy monitoring.

E. Premdas Pinto in his presentation highlighted the issue of bottom up knowledge generation from practice to countervail the top-down model of knowledge making and policy making. The contributions of COPASAH in terms of issue papers, case studies, stories of practice from various countries were highlighted. COPASAH knowledge products were also distributed to participants.

Renu Khanna, COPASAH Steering Committee member, from SAHAJ-Society for Health Alternatives (India) presented her reflections on challenges faced in independent monitoring of maternal and reproductive issues. These challenges were encountered in initiatives dealing with social autopsies of maternal deaths, monitoring negligence and denial of services to women through various community based efforts. This presentation was made as part of the session on '*Challenges of independent monitoring and advocacy'*. The session aimed at sharing experiences and reflections of practitioners who have been combining monitoring and advocacy to advance health rights. This session was chaired by Sono Aibe, Pathfinder. Walter Flores, COPASAH Steering Committee member, from Center for the Study of Equity and Governance in Health Systems (Guatemala) presented the citizen monitoring and community ethnography undertaken in Guatemala. The process was presented through a documentary followed by a presentation. Both visual presentations brought out the centrality of citizen empowerment, forming collectives and strengthening citizen voice as a sine qua non for monitoring and people centred advocacy. They also highlighted that when citizens voice critical questions, the system is likely to resist and also that there is possibility of back lash.

Conclusion: The small group discussions from the learning exchange deliberated on the critical research that would bolster the monitoring of reproductive health care and access to services. The themes of power, the research questions to be asked, various strategies that could be combined both at the grass roots as well as policy making level for improving access to reproductive health care, were also discussed. ■

About the Author

E.Premdas Pinto coordinates the Global Secretariat for COPASAH
Renu Khanna and Walter Flores are the Steering Committee members of COPASAH Global

Our Bodies, Our Lives – A Campaign for Better Antiretroviral (ARVs) in Malawi Enacting Social Accountability Through Women's Activism and Organising

SHEREENESSOF AND ALIA KHAN
JUST ASSOCIATES SOUTHERN AFRICA (JASS SNA)

1. Introduction

This case study was presented at the *Scaling Accountability: Integrated Approaches to Civil SocietyMonitoring and Advocacy* workshop organised by the Transparency and Accountability Initiative, School of International Service at American University, the International Budget Partnership and Government Watch of Ateneo School of Government, held between 18-20 June 2015, in Washington, D.C. It profiles the "movement building" strategies used by Just Associates (JASS), a non-governmental organisation (NGO) founded in 2002, that supports women's activism, leadership and organising for social change in Southern Africa, Mesoamerica and Southeast Asia. The case discusses JASS' work in Malawi, which began in 2007 as an effort to facilitate and support the greater participation of women living with HIV/ AIDS (WLHIV) in all matters entry into Malawi and the iterative process by which it worked with more than 1,200 WLHIV to strengthen both individual and collective voice and agency with the goal of transforming the structural drivers of discrimination, inequality and violence.

The case brings to light a more complex analysis of the drive to scale up access to anti-retroviral medications in countries hardest hit by HIV/ AIDS. Beginning with the global political declaration in 2001, the public health model for scale up is often described as a success. Indeed, millions of people living with HIV/AIDS have received treatment, and life expectancy for those living with the virus was increased. However, women's experiences, particularly in low-resource settings, reveal a more nuanced picture of success. Behind the impressive treatment targets achieved, WLHIV face multiple and intersecting barriers not only to accessing treatment, but also in enjoying improved health outcomes and wellbeing, which is arguably the more important measure of success. As illustrated in this case study, WLHIV's lives are mediated by a formidable set of institutions—formal laws and policies as well as norms and attitudes regarding gender, age, location, socioeconomic status, sexuality and more.

In the JASS' experience, focusing on policy change alone is not sufficient to improve women's material and social status and guarantee the full enjoyment of their human rights. Change strategies must affect shifts in the multiple spaces, visible, hidden, invisible[1] in which power operates. Power is often understood as fixed in relationships of domination and control, claiming *power within* and *power with* offers transformative potential for people marginalised and excluded by their social identity. Inturn, access to social goods and

[1] Visible power: observable decision-making. The formal rules, structures, authorities, institutions and procedures of politicaldecision-making. It also describes how those in positions of power use such procedures and structures to maintain control. Hidden power: setting the political agenda. Powerful actors also maintain influence by controlling who gets to the decision-making table and what gets on the agenda. These dynamics operate on many levels, often excluding and devaluing the concerns and representation of less powerful groups. Invisible power: shaping meaning and what is acceptable. The norms beliefs and ideological boundaries that influence how individuals think about their place in the world, this level of power shapes people's beliefs, sense of self and acceptance of the status quo. Processes of socialisation, culture and ideology perpetuate exclusion and inequality by defining what is normal, acceptable and safe.

resources can be more fairly and equitably negotiated and the promise of reliable democracy achieved. To do this, we must adopt change strategies that transform negative expressions of power—such as internalised oppression fuelled by discriminatory attitudes—starting at the individual level. Individual agency is a precondition of women's citizen engagement but often overlooked by the largely technical interventions adopted by mainstream development actors.

In contrast, JASS' approach to advancing gender equality starts at the individual level, working with women to strengthen critical political consciousness, identifying shared priorities, building solidarity and mobilising their *collective* voice and influence to affect the changes they wish to see. In the case of Malawi, this process-oriented approach, carried out over the course of nearly 10 years, has led to a vibrant movement led by community-based WLHIV leaders who successfully advocated for and are monitoring the accelerated roll-out of the WHO-recommended first-line ARV drug regimens in place of the lower cost, more toxic alternatives upon which scale up has been based in low-resource settings.

The *Our Bodies, Our Lives Campaign for Better ARVs in Malawi* provides a lens through which we can analyse the potential for women's increased citizen engagement and collective organising enacts social accountability—building the individual capacities, relationships and mechanisms to strengthen responsiveness and accountability between governments and their citizens. It offers an alternative to more tactical sector- and issue-specific interventions that often start with pre-determined solutions and do not tackle the structural drivers that create inequities in the first place. It is also an example of how organising campaigns around deeply felt priorities identified by activists themselves can serve as a vehicle for building an active and vocal citizenry to strengthen the "demand" side of governance and social accountability.

II. Strengthening women's leadership and organising in Malawi[2]

A. Setting the stage

JASS' entry into Malawi in 2005 came at a time of much reflection on the progress of women's rights and gender equality around the world. In the decade since the world's nations adopted the Beijing

Platform for Action, intergovernmental bodies and governments had begun to act on their commitments to eliminate discrimination and violence against women. Gender laws and policies were issued, and institutional mechanisms were established to implement them. Intergovernmental institutions, such as the CEDAW committee, strengthened their role in establishing and enforcing norms related to gender equality and human rights.

However, despite these markers of progress, women's material well-being, socioeconomic status and political influence overall showed little signs of improvement. The longstanding approach to development as a technical intervention prevailed. The once promising approaches of participatory development and gender mainstreaming had been reduced to mechanized processes, enabling politically liberal and conservative governments and intergovernmental agencies alike to tout their

[2] Report: Southern Africa Movement-Building Institute: Imagining and Building African Women's Movements, Johannesburg, South Africa, November 19-22, 2007, ActionAid international, the Open Society Institute for Southern Africa, and JASS (Just Associates). Report compiled by Shamillah Wilson, Lisa Veneklasen and Annie Holmes.

commitments to civil society engagement and women's empowerment while doing little to fundamentally alter the balance of power for those marginalised by their gender, sexuality, race, class, ethnicity, location, citizenship, religion, ability or otherwise. In addition, with the adoption of the Millennium Development Goals (MDGs) in 2000, the groundbreaking promises of the Beijing Platform for Action were reduced to a narrow, apolitical focus on girls' education and maternal mortality.

Meanwhile, HIV/AIDS was at the top of the global development agenda. In 2001, after decades of denial and neglect, governments finally made long overdue political and financial commitments to address the global AIDS pandemic. Unprecedented sums of money flowed from donor countries to those hardest hit by AIDS, generating billions in revenue for pharmaceutical manufacturers and the public and private institutions charged with HIV/AIDS prevention, treatment and care. This agenda had mixed implications for women's equality. It took several years, shocking statistics, and concerted advocacy by women's groups before the feminisation of AIDS in sub-Saharan Africa was acknowledged. In addition, while African women had been early pioneers in the fight against AIDS, African women's rights groups had been missing in action as powerful, gender-blind human rights and AIDS-service organisations battled over what to do with the vast sums of HIV/AIDS money.

Still, it was knew that women all over the world were surviving—largely on their own initiative and with few resources or recognition. They were responding to immediate crises, including natural and man-made disasters, climate change, and ruptures in the global financial system. Thus, the question before JASS was how to revitalise and strengthen women's movements and political influence to ensure that rhetorical commitments to gender equality were realised in practice.

B. Understanding the context (2007-2008)

In 2007[3], members of the JASS community, including colleagues working within Action Aid International and the Open Society Institute of Southern Africa, began exploring strategies to support the meaningful engagement of HIV-positive African women in shaping the HIV/AIDS response at both the global and country levels. Operating from a shared analysis that the global AIDS response had not acknowledged the gender dimensions of the pandemic, we worked with country partners to identify community leaders—women living with HIV/AIDS—to increase it's understanding of the context and lay the foundations for strengthening WLHIV's voice and agency at all levels of policy development and program implementation. JASS also reviewed national and regional policy frameworks and met with a range of development actors—bilateral and multilateral aid agencies, line ministries, and implementing agencies from the public and private sector.

On the surface, there had been some impressive developments. The African Union (AU) and regional economic and development communities, including the Southern Africa Development Community (SADC) had not only embraced their commitment to eradicating AIDS, but also set some of the most progressive and inspiring standards for gender equality and eliminating violence against women. Nationally, the

[3] The following account of this first regional convening is excerpted from the report of the SNA Movement Building Institute, November 2007.

Government of Malawi (GOM) had made the requisite commitments for gender mainstreaming and had embraced the WHO and UNAIDS' mantra of the "three ones"—one national AIDS agency, one national AIDS policy, and one country-level monitoring and evaluation system.

However, in order to understand the implications of the general lack of a gender analysis in country AIDS responses, JASS met with women who had been engaged in Action Aid's country programs and who are living with the virus as part of a needs assessment.

Within the context of development assistance, donors' competing agendas such as prevention vs. treatment, comprehensive sexuality vs. abstinence education, and the rapidly evolving aid architecture complicated the access to funding. Established women's rights groups had been slow to prioritize the HIV/AIDS, and tensions arose regarding the perceived 'diversion' of funding towards the epidemic. Within most groups of PLWHA (people living with HIV and AIDS), women lacked voice and power although they often were the largest, most active constituency within them.

Women all over Malawi bore the brunt of responding to HIV/AIDS in their communities, but they lacked mechanisms to share information, to combine resources or to mobilise their sizeable numbers for increased influence.

In conversations and workshops, JASS invited the women to talk about the more personal, day-to-day realities of their lives.

> *Women said that they need access to fertilizer, land, credit and good healthcare and talked about the pain and shame of HIV/AIDS stigma and violence as a result. They recounted verbal attacks, social isolation, and discrimination while accessing public resources such as federal fertilizer subsidies, food-for-work and cash-for-work public works programs, and microcredit loans. Much heralded home-based care programs had had the effect of exploiting women's already devalued care-giving roles, while letting governments and the international aid community off the hook for providing basic healthcare and essential services. Indeed, during the same two decades that the epidemic systems were further dismantled because of internationally-imposed neoliberal economic policies that favoured privatization and fee-for-service models, while capping hiring and salaries for professionals. This combination of factors left women disastrously overburdened, increasing their health risks while reducing their opportunities and ability to generate income or food.*[4]

Women's lived realities provided a more comprehensive and nuanced understanding of the context, including the discriminatory attitudes and behaviours driving the feminisation of HIV/AIDS and positive women's marginalisation within social justice movements and society at large. There were also disconnects among women based on age, location, class and sexuality which we recognised as problematic for catalysing a cohesive political constituency of WLHIV.

C. Establishing the base (2009-2011)

Based on this needs assessment, JASS continued to cultivate relationships with and among WLHIV by organising

[4] The following account of this first regional convening is excerpted from the report of the SNA Movement Building Institute, November 2007.

movement-building workshops in each of the three regions in Malawi and at the national level. Many women had already formed or joined support groups to get and share information about living with HIV/AIDS, providing a natural foundation for mobilising and organised constituency of WLHIV. By engaging community leaders, the workshops aimed to cultivate women's activism and leadership by building critical political consciousness and imparting concrete skills in organising and advocacy.

Using conceptual tools like JASS' framework for mapping and analysing power, women were able to link their experiences of inequality to discriminatory norms and institutions, including rigid, traditional gender roles, taboos around sexuality, and stigma surrounding HIV and AIDS. In doing so, they were able to identify targets and spaces for change, ranging from village chiefs and committees that withheld public goods to faith leaders perpetuating misinformation about the virus, and families that blamed and punished women for contracting HIV.

Through their mutual sharing and analyses in a confidential and supportive environment, women named and validated their own experiences of discrimination, trauma and violence, enabling them to, over time, recognise and overcome their own internalised oppression—fear, shame, and isolation—that compelled them to stay silent and accept their fate as inevitable. At the same time, facilitators urged them to look critically at their own work, the survival and coping strategies that women had devised, that constituted a form of power not always recognised or appreciated. In recognising their own power, *power within,* women were encouraged and inspired to use their collective power and identify creativeways to solve concrete problems and improve their lives.

Over the course of our group discussions and workshops, we identified 25 community-based leaders who would ultimately serve as a core group of "political facilitators" with whom we could work to strengthen and support their community-level organising. Many wore multiple hats, closely tied to large-scale NGOs, while also serving on local committees, staffing informal networks, and maintaining extensive networks of WLHIV. Following the workshops, JASS visited many of these leaders in their own communities, recognising that there was still much to learn about the specific contexts women lived in and how best to support them. Based on our own experiences, we wanted to be sure that the enthusiasm and momentum generated by participating in skills-building workshops and connecting to other likeminded activists could be leveraged and sustained when activists returned to their communities. As a testament to women's resilience and determination, we learned about the concrete progress they had made on priorities and action plans identified and developed during the workshop processes such as:

- Securing support from the National Association of People Living with AIDS in Malawi (NAPHAM) to raise awareness about uKupimbira, a harmful cultural practice that forces young girls to marry and drop out of school, increasing their vulnerability to HIV.

- Meeting with a village chief to discuss land rights for women and organizing 40 women to attend training on land rights, ultimately leading to two women being allocated land.

- Securing two additional mobile clinics to cover the most needy areas (Kafukule and Mphelemve) and another

attend training on land rights, ultimately leading to two women being allocated land.

- Securing two additional mobile clinics to cover the most needy areas (Kafukule and Mphelemve) and another two promised.

  In repeated meetings, we saw activists' health deteriorating. Community leaders shared stories of women throwing away their ARV drugs, convinced by traditional healers and faith leaders that they had been "cured" by their prayers. Countless other challenges were identified including stock outs of essential medicines to help combat opportunistic infections; lack of clean water and electricity, including at health facilities; erratic clinic and dispensary hours; even with the promise of universal access to HIV/AIDS treatment. WLHIV were at the mercy of a crumbling health system and weak infrastructure that effectively put improved well-being out of reach.

During all of our engagements, discussion groups, movement building workshops, and follow up meetings, we incorporated ample time for reflection and dialogue as well as unstructured time to connect at a personal level, often over raucus informal conversation, debate, singing, and dance. It was in these moments that problems related to the stavudine-based ARV treatment regimen were surfaced. WLHIV were experiencing debilitating health problems such as lipodystrophy (the redistribution of fat) and peripheral neuropathy (nerve pain and numbness). The enormous physical disfiguration caused bylipodystrophyfuelled HIV/AIDS stigma; in one instance, an HIV positive woman was nicknamed "Cyborg" by a man in her village. With little information about the toxicities and side effects of ARV drugs, many WLHIV did not know that their ARV's caused their health problems.

ElufeKabadwe was "surprised" when she learned that persistent numbness in her legs and arms, and a burning sensation from her legs during the nights was a result of the ARVs (T30 or Trimune 30, comprising of Stavudine, Nevarapine and Zidovudine) she was taking, 'How can the only drugs that gave me hope cause so much misery in my life? If it is indeed true that it is the ARVs I am taking causing all these problems then I would rather stop taking these drugs.'

D. The tipping point (2011-2012)

In order to increase our investments in Malawi, it became clear that we needed a local organisational partner to anchor and sustain our support. Thus, JASS Southern Africa entered into a partnership with the Malawi Network of Religious Leaders Living with HIV/AIDS (MANERELA+), an established NGO who had been instrumental in linking us to women community leaders during our assessment and start-up phases. Linking grassroots WLHIV with MANERELA+'s network of faith-based leaders and activists expanded the constituency and provided the organisational infrastructure to anchor ongoing training and outreach.

Through their community-based outreach, the core group of activists continued to hear stories about side effects brought on by WLHIV's AIDS medications along with their lack of access to treatment information and related services. Thus, they embarked upon a participatory action research (PAR) process in order to build the evidence base for a concerted campaign to demand access to better quality ARVs but which also served the goal of building women's leadership and engaging a broader

base of women that could be mobilised in the campaign. More than 60 activist leaders from all the three regions of Malawi participated in workshops on research design and interviewing skills, collaboratively creating survey tools that were ultimately used to interview 856 WLHIV from 13 districts in the North, Central, and South regions. Some of the key findings were:

- Most women interviewed were on ART, but only 52% knew which drugs they were taking; among those, 70% were on a Stavudine-based regimen while only 14 women were on the newer Tenofovir-based regimen known to have fewer side effects; according to one researcher, "…*many women do notknow the names of the drugs they are taking, and they receive half- baked information from hospitals about drugs."*

- 73% of women reported experiencing side effects including paresthesia (numbing prickling tingling sensation), lipomas (fatty growths) and lipoatrophy (fat wasting), yet most (80%) reported that they were not routinely assessed for ARV side effects during clinic visits; Women related how their bodies had changed in 'bad' ways- breasts, stomachs, and/or necks had become swollen or shrunken; in some cases dzanzi (paresthesia) was so severe that they could not walk. Activist researchers documented women's loss of self-esteem, "*My body is destroyed*;" "*My body is not beautiful anymore*;" "*I am looking like I am old*;" "*I am ashamed of myself because of the way I look*."

- Women who were interviewed talked about how their relatives looked after them; supported them financially and reminded them to take their medicines on time. But many also shared their experiences of stigma and discrimination, often as a result of how their bodies had changed on ARVs. Even if they had chosen not to disclose their status, it was apparent just by looking at them, *"Everybody now knows Iam taking ARVs because of the shape of my legs. This is not how I looked like before I started taking T-30"; "People know I am positive by sight."* They reported being mocked in the community and theworkplace, "*People are laughing at me*;" "*I am not a happy woman anymore because wherever I gopeople point fingers at me*;" *"Our children get mocked at school;" "People mock me saying I am pregnant."*

- Women reported that clinics often do not ensure privacy and confidentiality, and many encountered health workers who were poorly informed and/or who lacked respect or kindness toward WLHIV: *"Ineed to change medicine, but they said I must continue with this because I look more okay than others whose bodies have been more deformed"*. Both positive women and clinic staff reported a lack ofroutine testing for side effects, the lack of testing machines, and unavailability of Bactrim (assists in preventing infections). *"Since 2004, my CD4 has not been tested" and "My immunityis deterioratingbut the hospital say they is nothing they can do unless I find my own means of getting tested of my cd4"*

- Women said they were advised to eat a balanced diet, but almost all the women interviewed -94% - said they did not have enough food. Women also reported being denied subsidy coupons for fertiliser due to their positive status. *"Healthy food is also a problem. The chief doesn't give HIV positive people coupons, he says 'they are already dead."*[5]

The evidence was overwhelming, and the research design called for an

[5] *Activist Research Process* (Fact Sheet), Our Bodies, Our Lives, October 2012.

opportunity to synthesise and discuss the findings with research participants. This came to bear in the "National Dialogue on ART" held in Lilongwe and timed to coincide with UNAIDS' 2nd Global Race to SAVE Women's Lives. With a mobilised constituency women prepared for a national dialogue to launch the campaign and engage power holders to formulate and push their evidence based agenda forward.

The national dialogue began with a press briefing that brought together 20 journalists from national and community-based media houses including the national broadcaster Malawi broadcasting corporation (radio and television), Zodiac, Capital FM, The Nation and Radio Islam. Sibongile Chibwe Singini (of MANERELA+) and Mirriam Msewa (women activist leader from Paradiso T.B. Trust) shared a press release about the dialogue and fielded questions from journalists. The press conference generated much interest as evidenced by the presence of many of those journalists at the dialogue, feature articles in two national newspapers, daily news clips on national news as well as a 20-minute in-depth news special.

Creating Space for Women to Talk

The dialogue brought together more than 160 Malawian women activists together with key stakeholders and decision makers to build collective analysis and map demands for quality ART. Representing all three regions of Malawi, women activists celebrated HIV positive women's collective power and organising through song and dance. In addition to reporting on the research findings, activists were briefed by the Malawi Human Rights Commission and Malawi Health Equity Network, whose own work validated WLHIV's experiences and bolstered their claims. MANERELA+ leveraged its influence by arranging meetings between activists and Dr. Frank Chimbwandira, Director of HIV and AIDS at the Ministry of Health,.

Dr. Chimbwandira explained that the Government of Malawi had adopted the WHO's recommendations for a phased approach to discontinuing Stavudine and replacing it with the more expensive Tenofovir-based regimens, but that funding and challenges with supply and procurement remained. In response, women shared their experiences with gaps in local health systems, stigma and discrimination, eventually formulating a specific set of demands that were delivered to members of Parliament and then President Joyce Banda, who had appointed MANERELA+'s executive director as her advisor on NGOs and civil liberties. The demands were as follows:

- The scale-up of HIV prevention and treatment literacy programmes.
- Government prioritises our health and ensures 100% quality and access to ARVs for all Malawians immediately.
- Force pharmaceutical companies to provide quality, potent and cheap ARVs.
- Suppliers of drugs abide by WHO 2010 treatment guidelines and procure medicines with high potency.
- A 1% levy on profit of all large companies operating in Malawi for HIV programming.
- A minimum of 15% of national budget to be allocated to the Ministry of Health to support HIV programming/drugs in the 2013 – 2014.
- Government stop violating Section 30 of our Constitution: Right to Health by limiting access to new regimens to specific groups.
- Ensure access to CD4 count and viral load testing machines, and the availability of Bactrim at all health centers for all HIV positive people.[6]

Through a participatory process, the 160 women activists drafted a communiqué listing their demands to

[6] *Communiqué to the Minister of Health*, Our Bodies, Our Lives, October 2012.

the Vice President of Malawi). On the evening of the last day of the dialogue, armed with paint and paint brushes, women translated their demands into posters and placards in preparation for the March to S.A.V.E Children and Their Mothers from HIV Infections, Stigma & Preventable Deaths.

Movement Building in Faith-based Spaces

An Interfaith service held on the second day of the women's dialogue fostered new solidarities and linkages across religious difference and diversity. With over 200 congregants, and a wide range of denominations and faiths represented, women pastors and activists preached and shared their own testimonies, a dramatic presentation illustrating the difficulties of the current ART regimen for women and men. The service was a potent example of the effectiveness of movement building within faith-based communities. As a symbolic gesture, the congregation collected almost MKW 20 000 to take to the Minister of Health with an appeal to start a local fund for decent ARVs and better lives. A key issue being the high degree of external dependence for funding for HIV programming and the government's responsibility to find local resources to support ARVs and related programs.

Positive Women's Demands

Women activists' research to understand women's experiences of ARVs in their communities formed a key part of the campaign mobilisation, generating a string of urgent and provocative messages to President Joyce Banda and the Malawian Government. The devastating impact of Stavudine on women's bodies, the stigma and discrimination they experience, the need to connect women's access to quality to ARVs with access to other critical resources including fertiliser and savings loans in order to live healthy lives were just some of the demands women put on the table.

HIV positive women's demands were put to the principle secretary of the Ministry of Health through a meeting and the Minister of Health through a public march to SAVE lives as part of the SAVE conference. Audience was sought and evidence provided to President Joyce Banda an avid women's rights advocate for whom the stakes were high to ensure women's rights were advanced, in her own words, "*I will feel powerful when every woman in Malawi and Africa is free from hate and is empowered. I will feel powerful when women no longer have to lose their lives because they are abused…. I will feel powerful when women in Africa take their rightful place as equals.*"

Riding on the wave of the energy created by the national dialogue, the research and mobilisation, the now powerful constituency of women activists were geared up to hold the president to her word so that women's rights to safe, healthy and fulfilled lives could be made real. The visibility and public pressure generated during the dialogue both through the media, direct action and inside advocacy with the Banda administration helped create a tipping point that led the Government of Malawi to announce in 2013 that it would accelerate its rollout plan, eliminating the phased approach that had previously made the less toxic regimens only available to pregnant and breast-feeding women and those with higher viral loads. Although sustained funding for and delivery of the drugs are still significant obstacles, the announcement represented a swift victory for WLHIV.

E. Scaling up (2013-present)

Since the Our Bodies, Our Lives campaign was launched in September 2012, district focal points and campaign committees were established throughout the country to monitor the rollout out of Tenofovir-based ARV regimens and help women

barriers to access. MANERELA+ programme officer makes routine visits to districts, collecting and consolidating data from activists and comparing it with treatment data compiled by the Ministry of Health. Currently, there is a campaign presence in 24 of Malawi's 28 districts, and in villages where WLHIV are organising other women, there is 100% conversion to second line.

Focal points report better relationships between WLHIV and Health Officers and increased access to multiple drug regimens, essential medicines and mobile health services. Women who have started the new drug regimen have seen a reversal of side effects. More women are speaking out, thanks to their engagement with the campaign and movement building "schools" which are reaching out to more and more women at the district level. In some cases, barriers to access services is resolved by providing WLHIV and health care workers with accurate information, while others require more concerted efforts. For example, accompanying WLHIV to confront health workers at dispensaries where they were previously denied the new drug regimen. The impact on individual voice and agency can be seen in campaign leaders and political facilitators who have taken on more visible leadership roles within their communities, as Ellen, an activist from Nkhata Bay recounted,

In my community people living with HIV are on new drugs because of the Our Bodies, Our Lives campaign I took the initiative and went into schools to engage with girls and even the teachers to empower the girls and discourage them from early marriages so that they can pursue their education. I did this in 13 primary schools in Traditional Authority (TA) area, Malanda, because girls marry early in our area. I was elected to be in DACC (District Aids Coordinating Committee) to represent people living with HIV. This month, DPD (District Planning Director) told me that they have chosen me as a representative of PLHIV in the district. I went to pursue the issue of fertliser coupons with the Members of Parliament (MP) in my area and I also met with the counsellor and they said they would provide fertiliser to people living with HIV next year (as she is new). I have been part of JASS processes and this has enabled me to keep meeting influential people. In the past, I had a lot of fear and would ask myself, 'how can 'I' talk to the people in power, and tell them we want ARVs. Now we are not afraid of anyone as we know some strategies on how to speak to influential people.[7]

Leaders of the campaign have taken their demands to Malawi's Global Fund Country Coordinating Mechanism (CCM) and joined forces with national treatment activist and advocacy organisations around issues such as sustained and predictable funding for AIDS treatment.[8] They have taken their treatment literacy campaign to the airwaves, broadcasting on national and community radio stations and are envisioning ever-broader goals, such as increased access to livelihood supports and the establishment of savings clubs that double as organising bodies for women's practical needs and strategic interests.

In 2014, activists began concerted efforts to address the low levels of treatment literacy using a model of supporting and equipping community organisers with information and resources to educate other WLHIV about drug side effects and lifelong adherence. However, poor infrastructure, lack of transportation, time, resources and language barriers

[7] Looking Back to Look Forward, Report of Consultation with Women Activist Leaders of the Our Bodies, Our Lives Campaign, Lilongwe, JASS, September 2014.

[8] Letter to the Malawi Global Fund Country Coordinating Mechanism (July 2013) and A call for increased sustainable financialresources PLHIV sector in Malawi Beyond 2015 (open letter), June 2013.

makes complete geographic coverage difficult. Despite significant shifts, numerous challenges remain for the overall wellbeing of WLHIV including lack of educational opportunities, early marriage, gender-based violence and weak governance structures to ensure transparency and accountability for local and national budgets.

III. Implications and insights for social accountability

The Our Bodies, Our Lives campaign boasts of several characteristics described as important components of social accountability.[9] JASS' engagement with WLHIV in Malawi has always been conceived of as a long-term investment, and the campaign an ongoing effort to build the voice, visibility and influence of the activists with whom we have worked. The information upon which the campaign is based is user-defined i.e. it is activists' own research and experience regarding their access to ARTs and their overall wellbeing that shapes their advocacy demands and mobilisation. Our approach to movement building, by design, builds and aggregates voice and uses interlocutors to leverage women's collective power with decision makers. The combination of local, national and international advocates, and their relationships with decision makers create a dynamic, proven pathway to change. Moreover, while not yet fully realised, the campaign has laid the groundwork for achieving accountabilities of scale i.e. a standing and vibrant constituency with organisational infrastructure and support able to network and consolidate two-way coordination and campaigning in real time.

The movement building approach employed by JASS and its allies also offers additional insights into how strengthening voice, agency and collective power among a historically excluded constituency, WLHIV in Sub-Saharan Africa, can *enact* social accountability. That is, an active, informed, and organised constituency actively identifies its needs, claims its rights and sustains a dynamic and influential relationship with the state to effect tangible changes in their own lives. JASS' movement building model is based on the following assumptions.

- People in the margins are uniquely equipped to identify and challenge systemic discrimination and offer alternative models or the provisioning of social goods; building critical political consciousness enables them to recognize and mobilise intrinsic sources of power, develop a sense of agency, engender a vested interest in advocacy efforts and drive change on a sustained basis.
- Collective power is needed to give influence tomarginalised voices and cope with the inevitable backlash that comes with challenging traditional power relationships and the status quo.
- Mobilising individual and collective agency and voice is a long-term ongoing process whereby those on the frontlines of struggle need support.

In practice, these assumptions translate into common approaches that have been tested and proven effective in multiple contexts. Specifically, we start with individuals and their lived experiences. Through women's own reconstruction of historyand analyses of their lived experiences alongside the driving forces behind them, women can unpack and name the sources and forces of their structural inequality. Building critical political consciousness is key to increasing women's sense of self and

[9]Jonathan Fox, *Social Accountability: evidence really say?* GPSA Working Paper No. 1, September*2014*

agency, which is a crucial step in the transformative processes in which activists' deeply felt the needs form the basis of an organised, collective action. For outside facilitators, this implies supporting open-ended processes, working *without* a pre-determined agenda or intervention and instead creating the time and space for activist to identify and build on their own priorities.

Safe, women-only spaces enable solidarity and the mobilisation of collective power. Establishing a safe, supportive, learning space is crucial for developing women's individual and collective agency and power—a space where women can be honest, feel respected, laugh and cry and explore their journeys, challenges and connections, particularly in environments in which women are taught to stay silent. A variety of participatory methods and analytical tools are used, from storytelling and sharing survival and self-care strategies to creating moments for critical reflection and questioning, interspersed with time for relaxation and renewal. These spaces allow women to surface shared experiences, question inequality, identify their own strengths and resources, and develop comprehensive advocacy and political action strategies.

Conceptual and practical tools such as the power analysis allow activists to map and carry out transformative strategies of change. While many development interventions and strategies focuson the most visible forms of power, laws and policies, analysing the multiple spaces in which power operates, visible, hidden and invisible, offers a road map for shifting both formal and informal systems of oppression. Change strategies that acknowledge and address hidden and invisible forms of power are necessary to create the conditions in which progressive policy change has a meaningful impact through its consistent and effective implementation.

Ongoing mentoring and support, including resources for women to continuously connect with each other, help internalise learning and engender ownership. JASS plays a facilitative and catalytic role in bringing diverse groups of activists and allies together and supporting them when they return to their communities. Learning is internalised as women apply new conceptual frameworks, gain confidence from their success, and come back together to share, reflect and troubleshoot. As an external ally, the JASS' accompaniment can help women break through entrenched power relationships and inertia, for example intervening with organisational leaders or other community members as an “honest-broker”, helping to create the conditions for women's successful activism.

Broad-based, flexible alliances are critical. In addition to aggregating women's voices, working with and through formal organisations and networks is necessary to gain advantage with stakeholders. JASS' partnership with MANERELA+ provides credibility, advantage and access to national-level advocacy organisations and decision makers intimately involved in the national AIDS response. However, campaign participation is not predicated on organisational affiliation. Many community activists with whom we work with wear a many hats, combining membership of national groups, such as COWHLA with local bodies and alliances such as the Women's Forum, and their own community based organisations and networks.

Attending to activists' wellbeing must be a political priority in advocacy campaigns. Challenging the status quo, particularly entrenched gender norms, generates backlash, stigma, and isolation, including from family members, friends and co-workers. Such backlash is a political tool that can effectively stifle the urge to speak out, whether through fear and/or sheer exhaustion from fighting a long-term battle in which progress can be incremental. For WLHIV in

particular, prioritizing their own health and well-being is not only necessary for survival, it is essential for sustaining their leadership and voice. To that end, all activist gatherings create space for women to check in with each other and themselves about their physical and emotional health and build in time to learn and practice self-care, such as meditation or learning about alternative healing therapies that use inexpensive, readily available local herbs.

IV. Conclusions and the way forward

We believe that movement building offers the missing link to more tactical change strategies that are largely de-personalised and do not build in the iterative, long-term processes that enable individual learning and transformation ; cultivate mutually beneficial, meaningful relationships; and transform mindsets, the invisible belief systems, norms and institutions that entrench discrimination and stifle more egalitarian change. Nevertheless, our approaches are not without gaps and limitations identified through thoughtful debate and engagement with practitioners from more institutionalised environments, such as development agencies and academic institutions. For example, Fox also identifies elements of promising social accountability efforts that JASS' movement building approach has not touched, namely, building the institutional capacity for accountability on the supply side of governance. For an approach that is, by definition bottom-up, what is our role and entry point for catalysing change from "the top" or the inside? In addition, to what effect are positive incentives and negative sanctions useful in contexts where governments are equally, if not more so, influenced by external, regional and global actors, as opposed to their own citizens? Similarly how do organisations protect the benefits gains and continue to mobilise for monitoring of implementation after a win and what are the challenges of that? How do we identify where the breakdowns in implementation are happening (for example, local clinic level and national government) and what would it mean for our strategy in moving forward? What broad based alliances / structures are necessary in order to fully monitor policy implementation at all levels?

These and other questions point to the potential of more proactive, synergistic two-way dialogue and learning among more traditional development actors and activist-oriented "movement" actors who share a vision of a more equitable sustainable world for all people and the planet.

COPASAH is thankful to JASS for sharing the Malawi case study of engaging and organizing women.

About JASS

Just Associates (JASS), a non-governmental organisation (NGO) founded in 2002, that supports women's activism, leadership and organising for social change in Southern Africa, Mesoamerica and Southeast Asia. For more details visit www.justassociates.org

Continued from 9

to achieve the progressive realisation of the right of every person to health, and to the conditions and facilities necessary to good health, and to health care services , including reproductive health care. (2) A person must not be denied emergency medical treatment. (3) In applying any right under this section, if the state claims that it does not have the resources to implement the right, it is the responsibility of the state to show that the resources are not available."

Going forward

1. UNHCO is mobilising citizens to consistently demand for the inclusion of the right to Health through a Television advertisement which is a mimic of the President of Uganda meeting with the electorates at a health facility;

2. Making the right to health an election issue and positioning it a citizen's top priority as their go for the ballot come 2016 general elections.

About the Author

Moses Talibit, is a Legal Officer with the UNHCO.UNHCO is a membership non-governemental organisation working in Uganda. Since its inception in 1999, UNHCO has been implementing programmes that advocate for a strong institutionalized platform that is able to articulate voices of consumers of health goods and services. UNHCO has championed the Rights Based Approach (RBA) to healthcare delivery and contributed to efforts to improve community participation and accountability. For more information on UNHCO, Pls visit: www.unhco.or.ug

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UNHCO and COPASAH East and Southern Africa (ESA) Regional Strengthening Meeting

Kampala, Uganda
26th – 27th July 2016

Since inception of COPASAH, the East and Southern Africa (ESA) member institutions have registered achievements as individual initiatives owing to knowledge acquired from Facilitated Learning Exchange Visits. These specific achievements need to be collated within the network to promote sharing and learning; and regional policy analysis and advocacy. Subsequently, UNHCO is implementing the activityin the region in form of the "Regional COPASAH Strengthening Meeting" on July 26-27, 2016.UNHCO as the ESA hub will bring together COPASAH members from the ESA region to build their capacity in learning and sharing, creating partnerships for sustainability, understandzing the trends in social accountability and exploring ways to strengthen the ESA network.

OBJECTIVES OF THE ESA REGIONAL MEET

- To explore alternative methods for the advancement of the COPASAH network
- To enhance sharing and learning within the COPASAH network
- To strengthen capacity of members in policy advocacy at regional level

The meet will see accountability practitioners from six countries of the ESA deliberating over two days in a host of sessions on social accountability.

SESSIONS

The sessions for the first day themed **Introduction to Health Rights and Responsibilities** would include deliberations over

- Trends in social accountability in Africa
- Social Accountability & Legal Empowerment
- Power Relations and Governance for Health
- Learning and Sharing within ESA COPASAH network

The second day sessions themed **Functions of Health Unit Management Committees**would premise the discussions on

- Policy Analysis and Advocacy - Moving from challenging to engaging with the policy process
- Publicity and Media Advocacy
- Experiences from participants Group work
- The future - Exploring Ways to Strengthen the ESA COPASAH network

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