

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

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1. Introduction

This case study was presented at the *Scaling Accountability: Integrated Approaches to Civil Society Monitoring 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, invisible¹ 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. In turn, access to social goods and

¹ Visible power: observable decision-making. The formal rules, structures, authorities, institutions and procedures of political decision-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 Malawi²

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 known 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 2007³, 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 its 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

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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 creative ways 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

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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 not know 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 I am 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 the workplace, “*People are laughing at me;*” “*I am not a happy woman anymore because wherever I go people 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: “*I need 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 of routine 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 immunity is deteriorating but 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 fertiliser 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 financial resources 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 to marginalised 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 history and 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

⁹Jonathan 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 focus on 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 depersonalised 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
