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## Participation, decentralisation and déjà vu: Remaking democracy in response to AIDS?

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### Abstract

Participation, decentralisation and community partnership have served as prominent motifs and driving philosophies in the global scale-up of HIV programming. Given the fraught histories of these ideas in development studies, it is surprising to encounter their broad appeal as benchmarks and moral practices in global health work. This paper examines three intertwined, government-endorsed projects to deepen democratic processes of HIV policy-making in Lesotho: (1) the ‘Gateway Approach’ for decentralising and coordinating local HIV responses; (2) the implementation of a community council-driven priority-setting process; and (3) the establishment of community AIDS councils. Taken together, these efforts are striking and well intentioned, but nonetheless struggle in the face of powerful global agendas to establish meaningful practices of participation and decentralisation. Examining these efforts shows that HIV scale-up conveys formidable lessons for citizens about the politics of global health and their place in the world. As global health initiatives continue to remake important dimensions of political functioning, practitioners, agencies and governments implementing similar democratising projects may find the warnings of earlier development critics both useful and necessary.

### Keywords

participation; decentralisation; democracy; HIV/AIDS; citizenship

### Introduction

Community participation has been promoted as a cornerstone of HIV scale-up efforts in recipient communities, touted as a strategy that will simultaneously ensure better biomedical outcomes, solidify citizen support of donor and Non-governmental Organization (NGO) initiatives, and reinforce the broader development ideals of good governance, civil society and accountability (Bristol-Myers Squibb, 2009; Kapilashrami & Brien, 2013; The Joint United Nations Program on HIV/AIDS (UNAIDS), 2001). With the rapid and unprecedented scale-up of HIV programmes throughout sub-Saharan Africa, a wide range of donors and international partners embraced community partnerships, the support of civil society organisations and celebrations of the ‘local’ as guiding philosophies and tools for programme implementation (Birdsall & Kelly, 2007; Edström & MacGregor, 2010; Low-Beer, 2010; Parker, 2011). One of the most long-lasting impacts of global HIV scale-up may

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be the way in which it has elevated the community to holy ground, while also expecting a great deal more labour and responsibility from citizens than ever before.

These moves are not without precedent. Initiatives that push for good governance, decentralisation and participation have fraught histories in Africa. A significant body of literature has documented and critiqued efforts to decentralise governance and increase citizen participation in development and health initiatives during earlier eras (see, for example, Cooke & Kothari, 2001; Peters, 1996; Ribot & Oyono, 2005). Yet among HIV practitioners and institutions, these goals remain largely untarnished, held to be good in and of themselves. Among researchers, such goals are viewed with more scepticism; in particular, a robust literature is now exploring the character and quality of civil society engagement, in addition to the transnational politics that shape much of HIV policy-making (see, for example, Birdsall & Kelly, 2007; Cassidy & Leach, 2009; Kapilashrami & Brien, 2013; Parker, 2011; Swidler, 2009). Far less research, however, has looked in detail at efforts to increase citizen participation and localise priority-setting for HIV (Campbell, Nair, & Maimane, 2007; Paiva, 2003). As I will argue here, some of these efforts capitalise on the broad appeal and early successes of AIDS activism, but supplant oppositional, citizen-driven mobilisations with top-down task-shifting onto already beleaguered communities. Regardless of their varying success, efforts to build participation and decentralise HIV policy-making are a crucial example of the power of scale-up to remake political worlds – involving changes in citizenship roles, perceptions of political functioning, and relations between the public and the institutions involved in global health programming.

During the advent of HIV programme scale-up in Lesotho, the government and its international partners initiated several programmes designed to (1) decentralise HIV decision-making (the ‘Gateway Approach’); (2) elevate the role of local representatives in determining HIV priorities (the ‘Essential Services Package’ [ESP]); and (3) increase citizen participation in policy dialogues (District and Community AIDS Committees). A closer examination of these efforts is valuable – not in order to tell yet another cautionary tale about the challenges of participation, but instead to tease out the complex tensions between genuine, well-intentioned efforts to make HIV initiatives more deliberative and democratic, and neoliberal approaches that treat ‘participation’ as good behaviour, ‘decentralisation’ as unfair devolutions of responsibility without rights and ‘civil society’ as implementing partners (see, for example, Ferguson & Gupta, 2002). Studying Lesotho’s efforts to develop more democratic approaches to HIV policy also provides an opportunity to think more broadly about the complex challenges implicit in the relationship between HIV scale-up, political process and citizen subjectivity. Ultimately, HIV initiatives like the ones described here have broad sociopolitical impacts: even when they do not achieve their stated objectives, they convey far-reaching lessons for citizens about forces of political change and the place of participation in political arenas increasingly shaped by the transnational machinations of global health endeavours.

### **Old dogmas, new tricks**

The prominence of activism in the historical narrative of the HIV pandemic is well known. It is a hard-won legacy, forged by patient movements throughout the North and South, whose

efforts challenged scientific expertise and bureaucratic irrationality, becoming models for innovative, grassroots struggles across the globe. Activists' efforts ensured that HIV would be seen not just as a pathogenic disease, but a political one (Bayer, 1992; Berkman, Garcia, Munoz Laboy, Paiva, & Parker, 2005; Epstein, 1996; Parker, 2011; Petchesky, 2003). In the global scramble to expand HIV programmes throughout resource-poor countries, however, the activist politics of AIDS ceded ground to expert-driven efforts to 'administer the epidemic' (Parker, 2000), even as activists were finally granted the treatment access they had long fought to secure.

The massive deployment of resources, technocratic expertise and policies, broadly known as 'HIV scale-up', has revived old development dogmas that complicate the activist legacies of previous eras. The past decade has witnessed a consistent grafting of development strategies onto new global health movements. For example, The Paris declaration on Aid Effectiveness emphasises 'inclusive partnerships' (Organisation for Economic Cooperation and Development [OECD], 2008); and the Ouagadougou Declaration on Primary Health Care and Health Systems in Africa, which emerged from the Paris Declaration, places community ownership, participation and partnerships for health as cornerstones of a new African health agenda (Somanje et al., 2010). Drawing on the language of the original 1978 Alma Ata Declaration, Ouagadougou recognises the importance of 'redistributing authority, responsibility, and financial resources' but nevertheless offers little clarification about to whom, or what, this decentralisation should be aimed (Somanje et al., 2010, p. 12). And a 2001 report from UNAIDS defined decentralisation, multisectoralism, and community partnerships as key aspects of a strategic approach for building 'AIDS-competent societies' in recipient states (2001, p. 1). Much of the dialogue around global health governance reiterates these goals in equally vague terms. But decentralisation, partnership and participation are much older tropes: as histories of development show, these goals are not inherent goods. The vague ways in which they are deployed provides fertile ground for a productive confusion that contributes to further disenfranchisement.

Current efforts at decentralisation represent only the most recent resurgence of its popularity as a development strategy. In fact, the modern origins of decentralisation in Africa can be traced to the institutionalisation of 'indirect rule' by colonial administrators, who promoted 'traditional authorities' as a means of ensuring the subjugation of African populations (Mamdani, 1996; Ribot & Oyono, 2005). According to Mbembe (2001), the perverse power of colonialism was 'administered by a decentralised state apparatus – to be precise, by its agents – through specialized institutions, some of recent origin, some indigenous but reshaped for this purpose' (p. 28). One result of such rule was a reinforcement of a '*régime d'exception*' – an institutionalisation of legal exceptionality that buttresses sovereign power (p. 29; see also Agamben, 1998).

Decentralisation regained popularity during the development initiatives of the 1980s and 1990s. In Ferguson's (1994) analysis of a rural development project in Lesotho, decentralisation was implemented as an 'apolitical administrative reform' (p. 133), while development agencies failed to comprehend the bureaucratic structures of the nation state as actual *political* entities. With the advent of structural adjustment programmes in Africa, decentralisation joined efforts to empty out the civil service, shift resources away from social

services, derogate responsibility to non-state entities and ‘responsibilise’ citizens to meet their own needs in the absence of state protection (Ferguson & Gupta, 2002; Pfeiffer & Chapman, 2010). Citing old colonial patterns of subjugation, Ribot and Omoyo (2005) argue that ‘today’s decentralizations also appear to be proceeding in ways that risk reproducing old patterns of indirect rule: administratively driven local authorities managing people in the name of self-determination’ (p. 206). Though often touted as a measure for localising democracy, decentralisation can be acutely depoliticising, remaking the schizophrenic dualities of colonialism, where claims to decentralise rule enshrine the hegemonic power of an illegitimate ruler or set of rules.

Participation also gained popularity in the development movements of the 1970s, particularly as a strategy for subverting the top-down approaches of rural development projects (Chambers, 1992). Subsequent efforts to build participation often ignored the rich political cultures and histories onto which such projects were grafted, and evaluations of ‘participation’ often reflected the ideologies and political leanings of implementing agencies (Morgan, 1993). When programmes falter, fault is often found with the structure, character or desires of communities. But, as Lynne Morgan (1993) points out, these forms of ‘induced’ participation can hardly be compared with spontaneous, citizen-driven activism and its outcomes (p. 5). The close kinship between neoliberalism and decentralisation – what Robins (2008, p. 128) calls the ‘downsizing neoliberal state’s imperatives of governance-at-a-distance’ – was promoted by entities such as the World Bank, which embraced strategies like participation in so far as they offered solutions to the ‘political market imperfections’ that were undermining democratisation initiatives in developing countries (Keefer & Khemani, 2003). Such strategies reconceptualise citizens as conduits of information between rulers and the ruled in a machinery of efficient and cost-effective state functioning that is decidedly apolitical.

HIV scale-up took participation and community empowerment as central principles. Though scholars put forth important efforts advocating for forms of meaningful community participation and examining its challenges in the context of HIV programming that should not be overlooked (Campbell et al., 2007; Paiva, 2003; Robins, 2008; Seeley, Kengeya-Kayondo, & Mulder, 1992), public discourses of ‘participation’ and ‘empowerment’ tended to exacerbate the conceptual fuzziness of these terms (Morgan, 1993; Petchesky, 2003). As a result, HIV ‘participation’ took on discordant meanings: it could equally indicate, for example, putting on a condom, handing out a condom, endorsing the use of condoms among neighbours, or advocating for or against a condom-based prevention strategy with the government. Many programmatic uses still appear to conflate participation as a patient with participation as a citizen, though the postures and purposes of such forms of participation retain fundamental differences.

Scholars writing about biological and therapeutic citizenship trace biopower into new spaces of global health programming, exploring incursions that not only render bodies and the biological as a primary means and object of politics, but become themselves a prevalent and far-reaching form of governance (see, for example, Biehl, 2007; Fullwiley, 2011; Nguyen, 2008). These accounts are rightfully sceptical of empowerment paradigms: Nguyen (2010) adeptly describes the ‘confessional technologies’ that HIV patients must learn and deploy in

order to successfully access treatment. Discourses of empowerment and participation can act as disciplinary forces on patient subjectivities, constraining rather than widening the scope of possible action. Yet for many of my informants in Lesotho, the problem with HIV programming is not that it reaches too far into their lives, but that HIV represents a retreat of the state, its eclipse by NGOs and donors and its absence from public discourse with citizens – even as it became more and more accountable to external partners (see Kenworthy, 2013). Rather than solely examine the politics of HIV at the level of biological intrusions and interventions, it seems essential to examine the influence of HIV scale-up on the agency and subjectivity of citizens and the forms of public life that they value.

Like many countries, Lesotho struggles to reconcile HIV's global activist legacies with its domestic realities – in particular, the predominant logics of good governance and the lack of vibrant public mobilisations for HIV services. The relevance of Lesotho's efforts to build a more decentralised and participatory HIV response, for the purposes of this paper, is not to be found in any overt shortcomings, but in the pitfalls encountered despite genuine intentions to build a deliberative democracy around HIV programming. The initiatives detailed here demonstrate how conceptual tensions in decentralisation and participation became translated into multivalent struggles over political engagement. It is here – at the interface between discourse, policy, practice and citizen lives – that HIV efforts are conveying important lessons to citizens, local governments and ultimately states, about the new political dynamics of a post-scale-up world.

## Methods

In 2008, I embarked on a project to better understand the felt impact of scale-up's sociopolitical changes on the lives of Lesotho's citizens, community activists, patients, health workers and policy-makers. A critical, multisited ethnographic approach was used to answer these questions, involving participant observation and qualitative interviewing in social systems surrounding HIV treatment programmes in diverse sites. As part of the project, extended research was conducted with community councils (CCs), community AIDS councillors, NGO representatives, service providers and individuals involved in policy-making. Data from interviews and participant observation was analysed against extensive archival research and policy analysis. In addition to the above, this article draws on an in-depth analysis and compilation of existing evaluations of some of the policy initiatives described here (Chiyoka, 2009; Chiyoka & Hoohe-Nonyana, 2010; UNAIDS & MoLGC, n.d.).

## Lesotho: Scale-up amidst scarcity

Like a number of poorer countries in sub-Saharan Africa, Lesotho's scale-up was late coming, rapid and heavily influenced by external partners and policies. Though Lesotho still claims the world's third highest prevalence rate, 93% of all clinics now offer Highly-Active Antiretroviral Treatment (HAART) across all 10 districts (National AIDS Commission [NAC], 2011).<sup>1</sup> Despite the influence of external partners in Lesotho's scale-up of HIV programmes, the country is remarkable for its early and on-going efforts to ensure local ownership of programmes and a decentralised process of programme priority-setting. These

aspects of Lesotho's early response make its HIV politics particularly interesting as a case study.

By 2003 and early 2004, Lesotho's leaders realised that demonstrations of political commitment were essential to attracting HIV funding (see Gore et al., this issue), and they embarked on a top-down process of building political will. In 2004, the government released a detailed document detailing their vision and plans for scaling up the national response, titled *Turning a Crisis into an Opportunity* (Kimaryo, Okpaku, Githuku-Shongwe, & Feeney, 2004). A strikingly progressive document, it emphasises the importance of a multisectoral, participatory response attentive to structural determinants of HIV risk. The document outlines plans that focus on social and political metamorphoses to ensure a radical transformation of the health sector and HIV response, rather than only discussing the expansion of biomedical programmes. This was followed by the launch of a nation-wide testing campaign that, while controversial (Human Rights Watch, 2008), made Lesotho an ideal site for HIV programme scale-up for two reasons: it was a concrete demonstration of 'political commitment'; and it provided a ready population of already tested patients to enrol for treatment, at a time when agencies had significant concerns about countries' 'absorption capacity' for HIV funds.

These policy developments laid the groundwork for the three highly interrelated initiatives I wish to explore here: (1) The Gateway Approach, an initiative to promote CCs as 'gateways' for coordinating the local HIV response; (2) the creation of specialized Community and District Council AIDS Committees (CCACs and DCACs) situated within the local government system; and (3) The Essential HIV/AIDS Services Package, an initiative to involve councils in priority-setting processes for the HIV response and to mentor councils in implementing their own HIV/AIDS activities. My intention here is not to provide a thorough evaluation of any of these initiatives, but rather to understand them as a contested policy terrain upon which divergent ideas about governance, participation, decentralisation, accountability, and ultimately, the politics of epidemic response, played out.

### The Gateway Approach

In the same year that Lesotho launched its national testing campaign, the government, in partnership with the German Technical Cooperation (GIZ, previously GTZ) and UNAIDS, announced a new initiative called the Gateway Approach.<sup>2</sup> As a formalisation of the plans for a decentralised HIV response outlined in *Turning a crisis into an opportunity*, this strategy announced that communities – through local CCs – would now serve as the 'Gateway to fighting HIV and AIDS' (German Technical Cooperation [GTZ], 2006). In its original form, the Gateway Approach would engage communities in priority-setting processes to determine HIV-related needs and encourage NGOs and citizens alike to view councils as 'gateways' to intervention – arbiters of whether and how programmes should be run, putting community-determined priorities into practice. CCs would emerge as relevant local-level institutions for coordinating the response according to community need. In this

<sup>1</sup>Unfortunately, <70% of those in need of HAART were able to access it in 2010, and further expansion has been stymied by funding shortfalls (Médecins Sans Frontières, 2011; NAC, 2010).

<sup>2</sup>In Sesotho, the Gateway Approach is often referred to as *Khoro*, which means an entrance, or a mountain pass.

sense, the Gateway Approach was a novel and promising strategy: If any country was going to succeed in utilising HIV scale-up to build, rather than to dismantle, democratic participation and civic action, surely Lesotho seemed committed to providing the fertile conditions for such a development. In addition, it seemed to represent an ambitious vision of how HIV scale-up and grassroots democratisation processes could become mutually beneficial.

From its very inception, however, the Gateway Approach was at the mercy of competing visions of what decentralisation and participation might mean in practice – as the following document from the National AIDS Commission (NAC, 2007) makes clear:

the Gateway Approach will be the main coordination strategy ... whereby the Local Authorities are the gateways in the holistic response against the epidemic within the district coordination mechanism. The goal of the gateway approach [sic] is to provide a platform for all stakeholders including NAC to successfully implement their strategies ... by involving the communities and their representatives right from the inception ... The approach aims to empower and make the local authorities and other local leaders HIV and AIDS competent and to promote a demand-driven support system at local, district and national levels. (p. 2)

Here, the language of a ‘demand-driven’, ‘holistic’ response that directly involves communities comes immediately into conflict with a strategy that aims to use local government to ‘implement’ the ‘strategies’ of the national government and plans to ‘make’ communities ‘HIV and AIDS competent’. Without a clear vision or any means of monitoring the policy’s implementation, it quickly became unclear which way programmes, priorities and empowerment were moving through the ‘gateway’ – whether from communities towards NGOs, donors and government, or from those institutions into communities.

In practice, many service providers and partners ignored the aims of the Gateway Approach. In an inversion of the policy’s original intent, councils and service providers became gatekeepers through which community members had to pass in order to access powerful agencies and donors. Councils struggled to serve as coordinating institutions, having never solidified a role overseeing NGOs, service providers and donors (Chiyoka, 2009, p. 19). ‘The roll-out of the Gateway Approach is yet to be fully understood and “accepted” by all players’, an official assessment reported, ‘[as a result], stakeholders continue to implement their interventions with no consultations or communication with the [councils]’ (Chiyoka, 2009, p. 19). Councillors with whom I worked more closely agreed that NGOs would sometimes come to meetings and ‘announce’ their plans, but rarely engage in meaningful consultations. As one representative explained:

You don’t know who is in charge of what. Between the NGOs and the councils, [the councils] are never sure who is responsible because today [the NGO] comes with one guy, and the next time they come with another guy ... and there is no follow-up of issues.

Often it seemed that councils themselves were held responsible for the lack of coordination, as government officials blamed councillors’ lack of knowledge, training, and ‘capacity’.

Invocations of councillors' 'ignorance' were common, even from community members. Mme 'Mamaseko, a nurse, explained:

We know that money has been given to the councils to help us, but the people in the council are old and ignorant, they are not knowledgeable about HIV ... They are supposed to be the 'gateway'. We are familiar with the Gateway, we know that we are supposed to do everything through the council, but we struggle to get anything through them.

Mme 'Mamaseko thought the councils lacked 'relevance' and, because of it, suspected they let HIV money 'go back to the politicians' rather than staying in the community where it was needed. Instead of the council coordinating with actors 'above' the community, the community itself 'struggle[s] to get anything through them' that they need to accomplish.

The perceived weakness of councils in the face of NGOs, donors and politicians also made them prone to accusations of corruption. Mme 'Mats'eliso, a support group leader who worked closely with her council, explained that the Gateway Approach was 'not working out. It doesn't work at all. It never worked'. When I asked why, she explained 'the councilors never took it to *the people*. They were supposed ... we were expecting them to take it to the village level, but they implemented it for their own good'. Caught between those who orchestrated the HIV response 'up there' and those who were meant to be their constituents 'down here', councils lacked legitimacy but were viewed with distrust by citizens. Yet Mme 'Mat'eliso was also ready to admit that the council simply became 'rubber stamps' on HIV policies handed down by the government, and commented that civil servants and other agencies 'just overpowered them in their own office ... [the councillors] don't have their own voice'. Drawing on an interesting dichotomy between what she saw as the expertise of civil servants and NGO workers and the council as community representatives, she explained that, although she blamed the council for its poor implementation, she also understood its hands were tied because of the power differentials between the council and those with whom it was supposed to work:

They are just keeping quiet, keeping quiet ... because they are scared of them [the government, NGOs, and other agencies] ... because they are educated and qualified. *But as villages we are appointing [councillors] because of their integrity, not their qualifications.* [emphasis added]

What she highlights is, in fact, a normative disjuncture – between what is of value to communities, and what is prioritised by HIV scale-up.

### **The Essential HIV/AIDS Services Package**

In the year following the launch of the Gateway Approach, CCs across the country were led in an HIV/AIDS priority-setting process referred to as the 'Essential HIV and AIDS Services Package', or more commonly, the ESP. The process was ostensibly designed to decentralise decision-making and priority-setting on HIV to councils, and was spearheaded by UNAIDS, GIZ, the Ministry of Local Government and Chieftainship, and the National AIDS Commission (NAC), with funding from the Global Fund and, later, the World Bank. The initial phase of the project presented councils with five different categories of



‘objectives’ in the HIV/AIDS response: ‘Prevention through change in sexual behaviour’; ‘Access to HIV testing and health services’; ‘Prevention of mother to child transmission’; ‘Orphans and vulnerable children’; and ‘Support for people who are HIV-positive’ (Ministry of Local Government and Chieftainship [MOLGC] n.d.). Within each category, councils were instructed to select and rank their top three priorities from predetermined lists of possible interventions, which had been drawn from the National Strategic Plan on HIV and AIDS (the priorities and interventions are listed in Table 1). Each council received a handbook describing the possible interventions in more detail, including specific templates for interventions, ideal outcomes and benchmarks for measuring success (MOLGC n.d.).

After CCs chose priorities, they were given small grants with which to implement their selected interventions, a pilot project to test whether councils could effectively manage projects. Some councils successfully carried out small-scale interventions, such as registering needy patients or orphans, coordinating trainings,<sup>3</sup> or organising condom distributions. Most, however, struggled to conceive of and implement interventions that met donor and government expectations. Some ended up giving out funds to needy families, or buying food or transport for sick patients – ‘interventions’ that seemed reasonable given community needs, but were difficult to justify to donors, or to account for in budgets (Chiyoka, 2009). Despite these many challenges, however, councils reported that the process had made them feel as if they had been granted the legitimacy to talk about HIV. ‘Our communities feel for the first time HIV has been brought to their doorstep’, one councillor reported, ‘[we] now know that the prevention of HIV and care for the affected is not [just] the role of NAC’ (Chiyoka, 2009, p. 32).

ESP processes have been used by the UN in other countries to help identify health intervention priorities, more often employed by experts as a tool for evaluating cost-effectiveness and comparing interventions to gauge which offer the best impact for the money (Ensor et al., 2002; González-Pier et al., 2006). Even in Lesotho, ESPs have more recently been utilised as a standardised, externally-selected set of primary health services that should be available through community-based health centres, used as a tool by which donors and global health partners measure health system effectiveness. Though the HIV/AIDS ESP in Lesotho allowed councils to select their own priorities, it is difficult to recognise the process as one that democratised priority-setting. Priorities were preselected by funders and experts, with implementation strategies also drawn from National Strategic Plans (which, along with other policy planning documents, are notorious for reflecting global priorities). Councillors scoffed at the limited choices they were offered, saying that the process ‘could not accommodate some of the issues’ that they felt were most important (Chiyoka, 2009, p. 10). Many councils simply listed additional interventions that they felt were equally important, and these self-chosen priorities show striking patterns of similarity, reflecting pressing and under-acknowledged needs faced by communities: acute food insecurity; a concern about vulnerable populations overlooked by formulaic HIV policies (like ‘herdboys’<sup>4</sup>); and educational and training needs for groups and individuals less often

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<sup>3</sup>. Many trainings were, sadly, implemented by hiring Ministry of Health officials to come speak to communities or councils at exorbitant rates. For some councils, this took up much of their budget.

reached with HIV messaging (UNAIDS & MoLGC n. d.). These priorities are outlined in Table 2.

In addition, some of the pre-determined interventions most commonly selected by councils reflected broader gaps and deficits in the health system, such as mechanisms for transporting critically ill patients, and the need for additional health worker training (see Table 1). Unfortunately, these priorities, though important to councils, were later dismissed by national stakeholders and the ESP organisers as ‘not within the scope of [Community Council] work and therefore ill-advised’ (Chiyoka, 2009, p. 23). It was ‘generally agreed’ that council-selected priorities were ‘not ... entirely realistic [or] sustainable’, as they were the responsibility of the Ministry of Health (Chiyoka, 2009). As a result, the ESP process implicitly taught councils that such priorities were out of reach, and that advocating for them was beyond their mandate. It subtly reinforced their subordinate position, and conveyed that the scope of councils’ influence and their realm for activism was highly constrained.

Ultimately, donors balked at renewing the council grants for priority implementation, in part because financial accounting had been so poor. Accusations of corruption and mismanagement were rampant. Those in government took this as evidence that future projects should not solicit community leadership, an observation that would further solidify centralised, expert-driven policy-making. One civil servant involved in the project suggested, upon reflecting on the outcomes of the ESP, that efforts be made to replace currently elected councillors with retired Members of Parliament (MPs) and civil servants who had the expertise he felt was necessary to make councils effective as policy-makers. Such sentiments reveal on-going tensions between participatory approaches as moral practice, and pragmatic realisations that technocratic expertise and non-democratic process is the most efficient means by which to achieve the goals of HIV scale-up.

Citizens were also sceptical of the results of this democratic experiment. Expectations were high, and many citizens presumed that councils had received large grants for implementation; in reality, councils were working with micro-grants of a few thousand dollars, and within the constraints of pre-determined interventions. In a dynamic that I would see repeated over and over again within communities when one institution or organisation received funding support, the perceived failure of the council to establish meaningful improvement opened up social fissures fuelled by distrust, disappointment and suspicions of corruption, as is discussed below.<sup>5</sup>

### **Community and district AIDS councils**

Following the ESP, AIDS committees were established in conjunction with councils at district and community levels. By the end of 2010 it was reported by NAC that almost 96% of CCACs were functional (NAC, 2007, p. 12). The purpose of this initiative was to establish a local, standing body responsible for coordinating the HIV response in communities. It was hoped that these bodies, whose representatives were drawn from many sectors and groups

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<sup>4</sup>Herdboys are young men – some as young as 8 or 9 – who spend long periods of time tending livestock away from home, with little access to education or services.

<sup>5</sup>Similar patterns of social fissure in Lesotho are observed by Turkon (2008), Coplan (1994), and perhaps most prominently, Ferguson (1994).

relevant to the HIV response (clinicians, PLWHA representatives, traditional healers, support group representatives, expert patients) would be more knowledgeable about HIV and better able to coordinate with NGOs, clinics and NAC, to continue working on the priorities set forth in the ESPs. Trained coordinators were also deployed to all districts as Community Council Support Persons (CCSPs) to help build skills and capacity among committees.

In 2010, I attended a national meeting to assess the implementation of CCACs and DCACs; in attendance were committee members and councillors from across the country. Though members were enthusiastic about their positions and expressed sincere commitments to addressing HIV in their communities, the general outlook was far from positive. Members were not clear on their roles or responsibilities, lacked basic knowledge about HIV despite training efforts, and repeatedly insisted that they had no idea how to fulfil roles as 'coordinators' of the response. In discussions at the meeting, it emerged that many communities perceived the committees as hurriedly put together, with little forethought about the selection of representatives. Both committee members and their intended constituents were unaware of the purpose of their role as representatives. One meeting attendee explained:

I don't even know where the idea itself came from that such committees should be established ... They went to the clinic and they told the nurse, 'we are establishing a committee of the council, we need a person living with HIV, can you give us someone living with HIV?' ... Even the nurse did not know what that person was going to do on the committee ... The only thing they [said] is that they are establishing a committee, but it wasn't clear what this committee would be working on ... or what their role would be on the committee.

Thus, while hoping to bring democratic decision-making and participatory processes to a local level, AIDS committees' confusion about their roles and mission, and their token representation of ill-defined interest groups, further muddied the local political terrain of HIV and AIDS responses.

Though AIDS committees were intended to bolster the coordination between local government, service providers, citizens and national government, official documents explaining their mandate emphasised localised implementation. They would design and carry out small projects, collect data, submit reports on activities to national entities, raise and budget funding, and develop and carry out monitoring and evaluation activities in their areas (Chiyoka & Hoohle-Nonyana, 2010). Not surprisingly, committees lacked the specialised skills necessary to do much of this work, despite well-intentioned training and capacity-building efforts. But CCSPs and other policy-makers tended to blame members' lack of ability on 'illiteracy', 'ignorance' and poor education among members, even though Lesotho has very high literacy rates.

Despite these limitations, committee members remained committed to fulfilling their 'advocacy' and 'coordination' roles by indexing HIV needs in their communities and trying to address those needs with limited support. Though many remained unaware of strategies for engaging in law or policy reform, and felt this was not a legitimate part of their duties, members were very active in mobilising support for needy patients from neighbours and

other community members. Without training on how to solicit funding or support from donors and NGOs, and without a clear mandate for working with such entities, councillors and committee members tended to appeal primarily to constituents for financial assistance during funerals, school meetings, *pitsos* (community meetings called by the chief) and church services.

In spite of their significant efforts, DCACs and CCACs remained marginal players in HIV efforts, often serving as labour for implementations in which they had little voice, but still being held accountable by communities for HIV outcomes. As one example of the double bind they occupied, NGOs would frequently approach the council or its committees, asking them to provide lists of potential beneficiaries in the community – orphans and vulnerable children (OVCs), caretakers, or sick patients – to whom they could provide support. So they solicited the help of support groups and volunteers to go through villages collecting names, talking to those in need of assistance. Names would be written down, needs catalogued. And expectations of future assistance were reasonable. Many times these names would be turned into data that made its way into grants or requests for funding – if assistance materialised, it frequently appeared years later, and was disbursed along the lines of revised priorities. For those who collected the names, it seemed a ruse: in response to one NGO that repeatedly requested information on OVCs, a community leader explained, ‘We keep calling the *pitsos*, calling the children and they take their names, but they are just toying with the orphans...we are now so discouraged’. For those who hoped to receive services, it was not a stretch of the imagination to assume that their councillors had failed them, or pocketed the assistance that never seemed to materialise. ‘They promised us, as people living with HIV’, one patient said, distraught, after another NGO’s disappearance, ‘that we would be given money ... we felt that maybe this disease of ours was important ... we were told ... they could help us to get payments. And they *lied*. In this way, initiatives that purport to decentralise and build partnership can in fact undermine community leaders' standing and legitimacy, while making them increasingly accountable to external partners or national priorities rather than their own constituents.

### Negotiating the right to govern

As institutions caught between NGOs, funders, initiatives and recipient communities, CCs and AIDS committees occupy an awkward position, lacking the power to adequately influence responses to the epidemic, but remaining an important symbol of partnership for NGOs and donors. In observing the on-going relations between councils and NGOs, government officials, funders and clinic staff, it became clear that councils were most often used to endorse new or existing programmes with the community, to identify and triage potential recipients in their local areas and to organise *pitsos* so NGOs could recruit individuals for new programmes, disseminate information, or conduct educational initiatives. It was not lost on Lesotho’s citizens that the original intent of the Gateway Approach was being inverted. As early as 2006, when Bill and Melinda Gates visited Lesotho, a local newspaper printed a picture of the couple with the caption, ‘The Gateway to treatment’, a play on their name that emphasised donors' real influence over HIV programming (Lekhetho, 2006).

Even though many donors and NGOs seem extremely sincere in their commitment to community partnerships, and view engagement with communities as a healthy democratic alternative to working with (at times) autocratic governments, the lived experience of citizens, committee members and councillors tends to be far different. Exchanges with NGOs were perceived as unequal, stressful and, at times, dishonest. Councillors and citizens reported that ‘these people’ just came and went, ‘disappearing’ for long periods of time. As described above, the constant movement of NGOs and programmes in and out of council areas causes considerable problems for communication and mutual accountability. When questions or problems arose, representatives had no one they could contact, no means of getting in touch with the programme’s managers. They were also unable to follow-up with programmes or initiatives that had been promised but had not materialised.

As one example, while I was working in a peri-urban clinic, some impoverished patients were on an NGO-supported food aid programme. One month, the food aid stopped suddenly; patients went hungry, and faced the terror of unexpected shortages. Patients continued to come to the clinic each month, lining up to wait for food to be delivered; each month they left disappointed and without answers. Clinic workers and local councillors were unable to help, as they themselves did not know how to contact the NGO, and noted that even from month to month different workers would deliver the food. As patients watched the inaction of their local leaders, frustration mounted and rumours of theft or corruption filtered through social networks. Many months later, I heard it mentioned at a national policy meeting that the programme had ended, having only had temporary funding for food packages. There are multiple lessons here: as the council’s true powerlessness was revealed, citizen trust waned and perceived corruption mounted. The tendency of external NGOs and partners to always seem as if they have ‘disappeared’ is significant for citizen subjectivities, as is their perceived inaccessibility. Finally, the temporality of many programmes – their shifting priorities, and the overlapping and competing mandates of different NGOs – poses acute challenges for accountability to citizens.

The ease with which projects or NGOs can usurp the power of councils is also striking, even when councillors clearly understand their mandates. As I sat with one council over a period of months, I watched in shock as it struggled to regain legitimacy with citizens after an American volunteer working with a nearby NGO reappointed the representatives of a local political committee, and arbitrarily imposed and collected a head tax to pay for one of the NGO projects (see Kenworthy, 2013). More often, however, NGOs in the towns in which I worked played a more proximate role to the communal tensions they left in their wake. By elevating councils to positions of responsibility without altering the cultures of practice through which organisations and donors carry out projects creates acute political problems at village and communal levels. In doing so, projects intended to improve participation and decentralise democratic practice end up incrementally eroding the very bedrock of political society and communal trust.

## Implications for the future

Architects of the programmes I discuss here might be tempted to fix such problems by further clarifying council and committee mandates or providing additional training. To do

so, however, ignores the deeply fraught histories of ill-defined strategies for improved governance. As conceived and carried out in the context of Lesotho's scale-up, such strategies deploy a conceptual fuzziness from which donors and national governments benefit, even when they fail to achieve their stated objectives. Despite common patterns of resistance to decentralisation efforts among mid-level bureaucrats, national leaders can see considerable benefits from such schemes. While they retain unquestionable power over budgets and policy development, decentralisation and participation schemes allow leaders to shift responsibility for implementation to local entities. For communities, participation comes with significant and unexpected costs, as they may find themselves less able to hold government accountable for lacking services, and find that their own 'ignorance' is blamed for poor outcomes. As outcomes are increasingly tied to the development of so-called 'HIV competent societies' in Lesotho, it is the presumed incompetence of citizens that offers a scapegoat for donors and governments alike when programmes do not succeed. Meanwhile, donors and NGOs continue promoting a strategy that is seen as a moral practice in global health efforts, such that participatory approaches provide positive outcomes even when more objective measures of results are remarkably poor.

As particularly ahistorical endeavours, global health projects take up the mantels of participation, decentralisation and community partnership with little heed for the fraught histories of these approaches. Yet those who have studied development and its various reincarnations must feel a keen sense of *déjà vu*. In a seminal article on the discourses of development, Hintjens (1999) argues that 'in recycling the language of grassroots social movements, aid agencies have jettisoned most of the radical practices associated with such language in particular settings' (p. 385). The appropriation of democratic sentiments by international agencies and campaigns masks what is often an entrenched reticence to cede power to citizens in recipient states – or even, for that matter, to view them as citizens, rather than 'participants'. As Sarah White (1996) argues in her critique of participation in development projects, participatory approaches 'may be the means through which existing power relations are entrenched and reproduced' (p. 6). Other critics go so far as to call participation a 'new tyranny' (Cooke & Kothari, 2001). Indeed, the conceptual meanings of these terms were emptied out long before global health embraced them. They were then deployed in the service of global and programmatic goals: as Ribot and Oyomo (2005) write, in Africa 'public and private are conflated by many practitioners who believe that democracy and decentralization are about letting anyone who is local make decisions and by believing that NGOs and other community groups represent the public' (p. 208).

Given the political history of HIV – and its legacies of engaged, even transformative activism – the appropriation of the language of deliberative, decentralised democracy by powerful donors, national governments and transnational NGOs has been especially insidious. What is enlightening about the efforts described here is that even very well-meaning intentions to deepen democratic processes in HIV programming were under-mined when orchestrated from above, in a country without a vibrant activist history, and amidst a broader political environment dominated by powerful HIV institutions and policies.

HIV scale-up efforts, and now, global health programmes, constitute powerful social forces within recipient countries. One of the lasting legacies of HIV scale-up may be what it

teaches citizens and communities about the roles they can and cannot play in both domestic and international politics. If the experiences of citizens with the ‘democratising’ projects described above are any indicators, it is likely that citizens are not fooled by the language of participation, decentralisation and community partnership when it does not translate into meaningful – and more equal – roles in global health planning. Though democracy has come to be viewed with increasing suspicion (both among social theorists and Lesotho’s citizens), wholly dispensing with initiatives that attempt to deepen democratic participation may be far too drastic. To do so would be to ignore the powerful desires of citizens in places like Lesotho to have more, rather than less, of a voice in policy decisions. But we cannot expect more equitable participation and policy-making to spontaneously spring forth from citizens or ‘the community’ in Africa’s recipient states, because they are informed by policy that they are empowered. Instead, we must expect more equitable means and measures of practicing global health from powerful donors, NGOs, bilateral funding institutions and international organisations. Rather than speak about democracy, we must speak about power: the fix will arise not from changes or clarifications of procedural rules or technical mandates, but out of the recognition of truly undemocratic inequities in global health practice. To continue to use the language of democratisation in initiatives that fail to address fundamental inequities between communities and institutions is to conceal the undemocratic tendencies in largely well meaning global health approaches.

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**Table 1.**

Ranked HIV priorities from 128 community councils in Lesotho.

HIV priorities from 128 community councils in Lesotho	First priority (%)	Second priority (%)	Third priority (%)
Objective 1: prevention through change in sexual behaviour			
Male-focused discussions	29.6	20.8	8
Facilitation of regular activities for youth such as football, volleyball, dance groups, drama groups and life skills groups	26.4	18.4	22.4
Distribution of male and female condoms and proper usage education	20	20	10.4
Building the capacity of traditional community leaders in HIV and AIDS and in implementing related initiatives	11.2	14.4	18.4
Parent involvement in shaping the behaviour of children on HIV and AIDS related issues	8	15.2	8.8
Registration of initiation schools and facilitating adherence to best practices within the schools	4	8	18.4
Building the capacity of church leaders in HIV and AIDS and in implementing related initiatives	.8	2.4	8.8
Facilitating the capacity building of business leaders in HIV and AIDS and in the implementation of related activities	0	1.6	4
Objective 2: access to HIV testing and health services			
Support mechanism for critical patients to [access] hospital/health facility (council to agree on the mechanisms)	25.6	27.2	17.6
Registration of chronically ill patients	24.8	20	14.4
Facilitate and ensure provision of HBC supplies and gloves and limited training to registered HBC groups	24	20.8	27.2
Registration of home-based care (HBC) support groups	9.6	11.2	11.2
Facilitate and ensure training of at least one health facility worker per facility to do HIV counselling and testing	8.8	8.8	12
Facilitate provision of testing kits to trained community HIV&AIDS counsellors	7.2	12	11.2
Advocacy for provider-initiated testing at health care facilities	0	0.8	4
Objective 3: prevention of mother-to-child transmission			
Provide training to at least on health facility worker per facility to do PMTCT and testing and ART/PEP support	36	18.4	16
Train CHWs to test and support prevention of mother-to-child transmission	33.6	28.8	24
Establish referral system for emergency delivery for mothers	16	29.6	36.8
Conduct door-to-door/community education campaigns and male involvement on PMTCT + exclusive breastfeeding	16	22.4	21.6
Objective 4: orphans and vulnerable children			
Registration of OVC	38.4	17.6	8
Ensure that registered orphans and OVCs have access to basic services such as education, nutrition and food security and health care	33.6	37.6	20.8
Capacitate and empower councilors, chiefs and community members in protection of OVC and ensure access to required services	16	26.4	45.6
Facilitate counselling services for orphans and OVC including support/play therapy	12.8	16.8	24.8
Objective 5: support for people who are HIV+			
Sponsoring HIV+ facilitators to do door-to-door, community gatherings and small group meetings /speeches/discussions on living positively with HIV/AIDS, stigma and discrimination	30.4	32	24
Placement of one 'expert' or HIV+ patient at each health facility	27.2	14.4	14.4

Note: Percentages of councils ranking each priority as primary, secondary, or tertiary within five categories of objectives.

**Table 2.**

Additional community council HIV priorities.

<b>Additional community council HIV priorities</b>	<b>Number of councils listing priority</b>
HIV education needs of special groups	99
Herdboys	38
Traditional healers	15
Support groups	13
Public servants (teachers, council, police)	12
Elderly	11
Disabled	10
Agricultural/nutritional needs of patients, orphans, affected families	55
Income generation or vocational training for vulnerable – especially orphans	14
Need for first aid kits/gloves in homes of sick and public places	10
Develop traditional/herbal medicines to treat HIV	5
Human rights and gender equality campaigns	4
Other improvements in clinic service/infrastructure	4
Need to train men in home-based care	2

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