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HIV/AIDS Policy: How to Readdress the Balance Between Global Provision and Local Civil Society?

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How are shifts in the global aid architecture affecting HIV/AIDS policy and how far are these in tune with (or disconnected from) the responses of local civil society? This paper analyses HIV/AIDS policy in relation to two shifts in the aid architecture – fragmentation of the health sector through global restructuring, and aid harmonisation. The objective is to address the disconnects that exist between global HIV/AIDS policy and civil society responses to the HIV/AIDS crisis. It suggests that greater attention needs to be paid to incorporating civil society voice within policy processes on HIV/AIDS and that this will require couching HIV/AIDS debates not solely in the domain of disease control but in the broader realm of public health. Without this the prospects for responses premised on assessment of need from those from below are likely to remain weak.

HIV/AIDS Trends in Africa

According to UNAIDS, a total of 39.5 million people were living with HIV in 2006 (2.7 million more than in 2004). The number of new infections in 2006 rose to 4.3 million. Almost two thirds (63%) of all people living with HIV globally live in sub-Saharan Africa – an estimated 24.7 million in 2006. Some 2.8 million adults and children became infected with HIV in 2006, more than in all other regions of the world combined. The 2.1 million AIDS-related deaths in sub-Saharan Africa represent 72% of global AIDS deaths. Africa's HIV epidemics are following divergent trends. There is evidence of diminishing or stable HIV spread in most East African and West African countries, along with signs of growing epidemics in a few countries. In southern Africa, only Zimbabwe presents evidence of a strong decline in national HIV prevalence. In several other countries – including South Africa – the epidemics do not yet show signs of abating. Across this region, women bear a disproportionate part of the AIDS burden: not only are they more likely than men to be infected with HIV, but they are also more likely to be those caring for people living with HIV. Thus, amongst the most susceptible are women and children (Save the Children, 2007).

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The emergence of HIV/AIDS in Africa has coincided with major restructuring of public service health provision. Privatisation of public services has led to growing inequalities in health care. Concurrently, responses to the HIV/AIDS crisis have been slow both within and outside Africa. With the exception of Uganda, national governments have largely failed to implement a public health response and international aid agencies alongside others have moved in to fill this space. In particular, since the 1990s there has been an increase in philanthropic funding for drug treatments. In terms of policy and response to the HIV/AIDS crisis, external pressure from domestic politics in the US has lead to a predominant focus on emergency care and treatment through antiretrovirals (ARTs). The Global Fund and PEPFAR[1] have entered with force as new supply chain players. Philanthropic funders, such as the Gates Foundation, have become powerful actors on the international development scene. These typically pursue strong business models that are outcome-oriented, with a strong focus on marketing products such as vaccines. Though ARTs can help fight these diseases, and a strong case can be made that they should be made less costly and more accessible (Christian Aid, 2007), concerns have been raised with "pushing" them into what have become liberalised and very unregulated markets.[2] Whilst private pharmaceutical companies have dominated the scene, preventive health care has occupied a much more secondary space. Similarly, the space for not-for-profits that were more formally regulated has been reduced (Mackintosh, 2007).

For donors this panorama presents several dilemmas: To what extent is the existing organisation of HIV/AIDS policy being premised on assessment of need from those from below? How is the international politics driving policy on HIV/AIDS in Africa impacting on local civil society? For example, little is known of how civil society in particular has been managing the effects of the AIDS pandemic. Is civil society able to use the donor funding for AIDS treatment spilling into their organisations or is there a risk that this funding may be swamping them and diverting them from addressing other issues?[3] Before examining the disconnects between global responses to HIV/AIDS and those of local civil society, two shifts in aid architecture need first to be understood: fragmentation of the public health sector and aid harmonisation.

Shifts in Aid Architecture: Fragmentation of the Public Health Sector and Aid Harmonisation

Fragmentation of the Public Health Sector

Responses to HIV/AIDS need to be understood from within a broader social development context and knowledge base since the AIDS debate is developmental and relates to public health sector issues which go beyond the medicinal or purely scientific. Thus in order to understand the disjuncture between the dominant responses to HIV and bottom-up approaches we must first set the scene in terms of global restructuring of health care and provision.

Losing public sector revenue puts pressure on households to fund health or leads to cuts in service provision (EQUINET, 2007) and, according to Qadeer et al (2001), changes such as the gradual dismantling of health care institutions, their receding resource base, introduction of user fees in public hospitals and opening up of medical care to the private sector have left the interests of the poor without safeguards. These measures were introduced with the inefficiencies of governments (particularly in

1 Bush's $15 billion AIDS programme known as the President's Emergency Plan for Aids Relief or PEPFAR.

2 The incentive for doctors to over-prescribe in this context as well as issues of safety and increasing chances of drug resistance especially in places where health infrastructures are very weak is a real concern. Second, vaccine production has become more central to the interests of the pharmaceutical industry with little questioning of the "tacit globalism of vaccine politics" (Bloom and Zanders, 2006:1826).

3 Interestingly, in surveys conducted with deprived groups in Africa other concerns arising from maldevelopment feature more highly or at least as on par with HIV/AIDS itself including for example, unemployment, crime, education, famine and other health priorities (De Waal, 2006).

Community conversations in Ethiopia about the challenges of HIV/AIDS.

Children attending a health festival in Tolonguina, Madagascar, hold a flag to remember those lost to HIV/AIDS.

the Third World) in providing democratic governance, upholding of individual rights and choices and efficient and participatory local self-government, being used as a main justification for the rolling back of the state. The second rationale for commercialisation in the management of pubic organisations was that of better value for money and quality of care (Sen, 2007); leading to the usurping of civil society as individual consumers, and with notions of the univeralism of health and social care slipping from the discourse.

The discourse around modernising healthcare systems and offering 'choice' by giving much more freedom to the market masks the actual effects of neo-liberal market-oriented policies and globalisation that have led to widening inequalities in income and health, and the shrinking of civic space. This has undermined social fabric in such a way to compound inequalities and differentiation in health outcomes between different socio-economic groups – with cuts introduced by reforms in the health sector having a disproportionate effect on the poor. Further, these reforms lead to the view that equity in healthcare could only be achieved through the mobilisation of multiple players (such as NGOs), with the role and financing of the public sector shrinking as it became to be projected as a mere 'partner' (Qadeer et al, 2001). In this context a multiplicity of actors use provision of healthcare to vie for broader power and influence. As argued by De Waal (2006), nowhere is this more apparent than in the case of responses to the HIV/AIDS epidemic in sub-Saharan Africa.

Aid Harmonisation

Governments in eighteen countries have now signed up to the aid effectiveness agenda (embodied in the Paris Declaration(PD)). The aid effectiveness agenda deals specifically with aid from donor governments and large multi-lateral institutions to Southern governments. The focus is on improving the public administration of aid, particularly within a setting of enhancing financial management. The principles upon which the PD is based are thus set within this largely administrative framework. The UK government and supporters within DfID have been pushing it quite heavily. This comes despite some reservations from particular departments within this agency that poverty alleviation, social policy, gender and human rights have largely been missed (INTRAC, 2007).

Northern NGOs have been supportive of the principles of the PD, but remain sceptical about the process by which the PD proposes management of aid (INTRAC 2007, SIDA 2006). For example, they have questioned its likely impacts, scope for inclusion of civil society actors, and, above all else, its ability to have a real impact on the lives of poor people, worldwide. In particular they fear the absence of civil society voice though poor consultation and opportunity for discussion around development priorities. This reflects the more general lack of recognition of the crucial role played by non-state actors in the development process.

In the broader policy environment of aid harmonisation, the role of the non-governmental sector, and particularly consultations between government and the third sector, are being neglected: "The Paris Agenda largely overlooks the non-governmental sector and yet non-profit and for-profit private organisations play a vital role in the development process, particularly in the health sector" (CORDAID, 2007). Maximising the comparative advantages of the third sector can be achieved through encouraging systematic dialogue and meaningful participation between CSOs and government, yet evidence of such participation is still relatively weak (INTRAC, 2007). Neglecting civil society voice risks maldevelopment in a sector where civil society voice is long overdue. Thus the broader aid harmonisation agenda needs to become more inclusive of civil society voice. Without this the prospects for civil society in other domains such as in consultation on HIV/AIDS policy is likely to remain weak.

Global Responses to HIV/AIDS in Africa

Foreign Intrusion?

The emergence of the AIDS pandemic coincided with far reaching restructuring of public service provision in Africa (De Wall, 2006). This has led to a lack of recognition of the role of the state in provision of universal social welfare and a much greater focus on the primacy of emergency care or treatment. De Waal argues that this has resulted in the growth of hybrid forms of public health organisation with high degrees of participation by national and international NGOs and foreign donors. Such external dependence on donors has, to a large extent, weakened domestic accountability (De Wall, 2006:53).

Denial of the problem (for example, due to taboo and moralistic issues constraining social abilities to respond to AIDS) has been widespread, with devastating effects both at the level of individuals, communities and organisations (James et al, 2007). This has further undermined political responses which have been typically weak, not helped, for example, by restrictions on the freedom of the press in many countries leading to failure to bring the issue to the attention of the public with more force (De Waal, 2006).

The inability of African governments to implement a public health response to HIV/AIDS in Africa (with South Africa being a notable exception) has been used to legitimate a multiplicity of actors moving in to fill this lucrative and high-profile space. These power brokers include for example, donors, foreign governments, private foundations, pharmaceutical companies, militaries, contractors, scientists, rock stars and religious groups as well as the donor-funded NGO sectors that mediate between these different groups (that are now being projected as constitutive of civil society whilst leaving others behind). In this context of restructuring of public service provision in Africa combined with the crisis of legitimacy of many African governments, AIDS provision is being externally managed: "Africa is partly scenery and Africans are mostly extras" (De Waal, 2006: 63). Thus, the response to HIV/AIDS has largely been patched together in a way that is uneven in terms of coverage and quality, responding in an *ad hoc* and unco-ordinated way depending on vested interests as well as availability and types of funds available from foreign players.

Focus on Treatment over Prevention

The West was too late in the first instance to respond to the impending HIV/AIDS crisis in Africa and largely ignored what was building up to be a huge humanitarian crisis (Easterly, 2006: 233). Since that time and mainly due to political pressure, certain policies or responses to HIV/AIDS have been heavily pushed with "aid for Aids" being mismatched and unaligned with the choices of the poor (Easterly, ibid:213). Thus it has been argued that political pressure led development planners to focus on the goal of treatment over prevention. Not only was treatment much for lucrative for pharmaceutical companies than focusing on preventative care, but also, other interest groups such as the gay lobby in the US also prioritised and promoted treatment. Given these competing pressures it would be "political suicide for rich countries to question Aids treatment" (Easterly, 2006: 221). Notwithstanding the benefits of ARTs to help fight diseases for those who can afford access to them (Christian Aid, 2007), this might explain why the response has been diverted away from other and less lucrative approaches less focused on short-term measurable results or outputs such as prevention of AIDS and other diseases such as malaria and diarrhoea. The extent of this political pressure is visible in the fact that worldwide in 2002 there were 15.6 million deaths from preventable causes and 2.8 million from AIDS. This raises the question: to what extent is the existing organisation of HIV- related services premised upon assessment of need from those from below?

Interestingly, in surveys conducted with deprived groups in Africa other concerns arising from maldevelopment feature more highly or at least as on par with HIV/AIDS itself, including unemployment, crime, education, famine and other health priorities (De Waal, 2006). Similarly, though there are 28 million

Community members in Rehoboth, Namibia assess how HIV/AIDS affects them through a series of peer group discussions, followed by a community meeting where results are shared with the larger community as a way to help fight the HIV epidemic in Nambia.

Radio discussion of the stigmatisation of HIV victims.

HIV-positive Africans, there are 644 million HIV-negative Africans (Easterly, 2006). Thus there would appear to be a strong case for preventing AIDS from spreading from one group to the other. Yet the political pressure for treatment appears to be what is conditioning responses to the pandemic more than assessment of genuine need. For example, it has been noted that pressure exerted by the religious Right in the US led to Congress mandating at least one third of the small PEPFAR prevention budget going to abstinence-only programmes, despite the fact that studies in the same country have found no evidence that these change the sexual behaviour of young people, except discouraging them to use condoms (Easterly, 2006).

Notwithstanding the benefits of antiretroviral treatment which is certain to benefit sectors of the population who can access them (Christian Aid, 2007), it is clear that the drivers of this focus on high-cost coverage, arises: firstly, not always out of health need but in part due to other pressures such as that of maximising revenue (as has been the case in global public health restructuring elsewhere); secondly, to pacify interest groups using 'solutions' predominantly originating out of concerns located in the West, rather than through consultative process on perceived need by those in the South. An exclusive focus on ARTs carries potential dangers of high opportunity cost in terms of diverting attention away from preventative care, but it is itself sometimes problematic to implement in practice.

First, vulnerability and poorer health of poorer segments of the population in general mean that ARTs are not suitable in all cases and may be unlikely to be as effective as other forms of care, or indeed counterproductive. Second, the rollout of ART runs the risk that strains of HIV that are resistant to first-line drugs will emerge. Third, such responses ignore social stratification and class analysis which seeks to explain how relational positions in social systems generate income-based and other inequalities. This diverts attention away from how differences of access to material resources are ultimately a product of political and ideological decisions with treatment serving as a 'quick-fix' without the need to give serious attention to more contentious inequalities in ownership of wealth and distribution of power (Mukityhapadya, n.d.).

In this context there is a risk that a focus on ARTs may lead to growing health inequalities – treatment rationing will lead to unequal access depending more on sources of funds and influence than any notion of universalism of care. There is also the issue of how the treatment is to be monitored, with more endemic and structural problems such as that of corruption undermining the effectiveness of ART use. For example, expensive ART has been sold by public health officials on the black market. This could encourage new strains of HIV that are drug-resistant. Such concerns have been noted in an article from the Journal of the American Medical Association (2004) cited by Easterly: "How will the tens of thousands of health care professionals required for global implementation of HIV care strategies be trained, motivated, supervised, resourced, and adequately reimbursed to ensure the level of care required for this complex disease? To scale up antiretroviral therapy for HIV without ensuring infrastructure, including trained practitioners, a safe and reliable drug delivery system and simple but effective models for continuity of care, would be a disaster, leading to ineffective treatment and rapid development of resistance."

A narrow focus on treatment through ART may also have indirect negative impacts. For example, the role for NGOs may in fact be undermined with them acting more as service deliverers or as "a mechanism to process donor funds to provide ART" (De Waal, 2006) than using their comparative advantage of autonomy from government to carry out other roles. These might include, for example, holding government to account, building strong networks with other actors and learning how to make these effective, working to develop and adapt existing strategies for capacity building in terms of HIV/AIDS responses at community level, or participating in national policy legislation on HIV/AIDS.

Civil Society Responses to the HIV/AIDS Crisis

How is international policy on HIV/AIDS impacting on civil society organisations (CSOs) operating at community level? Though very little research has been published in this area, increasingly, NGOs and CSOs are receiving contracts as service deliverers for international players such as IAVI (International AIDS Vaccine Initiative), supported by the Gates Foundation. However, there is still very little evidence that CSOs are being consulted in national dialogues on HIV/AIDS policy (Hankin, 2007). Despite signs of local mobilisation in some areas, the political space for civil society to participate in national policy making on managing the HIV/AIDS pandemic has been notably small. For example, civil society was given limited space for formulating national strategy on the Global Fund on Aids (Easterly, 2006). One exception to this has been the ANCS (Alliance Nationale Contre le Sida) in Senegal that worked with four other CSOs, establishing a watchdog body to critically examine the government's response to HIV/AIDS (IDS, 2006).

Notwithstanding conflicting interests and non-organised interests within civil society at large, in theory at least local civil society works more on the basis of contextual need and citizenship and is motivated less around AIDS control led by international politics. Though to a certain extent civil society is itself socially embedded and constrained in terms of only being able to act according to the context and norms set within the confines of the society out of which it has emerged (Harrison, 2007), local civil society holds that responses to HIV/AIDS should be driven less by political and institutional interests but rather out of need as defined by those in the South.

Following such guiding principles, the response of local civil society has been to concentrate on activities that are the least profitable, such as working on prevention, health promotion, community based educational interventions and broader health interventions including mother and childcare (Sen, 2004), in areas where the increases in costs following privatisation have resulted in vast sections of the population being denied healthcare (Qadeer et al, 2001).

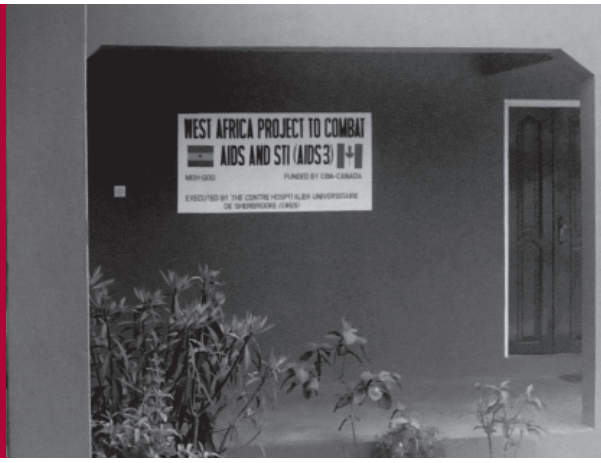
Yet, local NGOs, volunteer organisations and community-based organisations themselves are not immune to the effects of HIV/AIDS. Acute psychological strain and burden at the individual staff level as well as loss of productivity of those engaged in community-based activities, is increasingly threatening organisational sustainability. Some work has already taken place into how CSOs are learning to manage the HIV/AIDS pandemic at an organisational level (James et al, 2007), but the impacts of changes in the wider aid architecture influencing policy towards HIV/AIDS have been very under-researched.

In some cases it has been evident that the strain placed on families and local communities to provide home-based care has diverted them from attending rallies and political protests to raise the profile of HIV/AIDS at national and regional levels. By contrast, in countries such as Tanzania, Mali and South Africa, AIDS has created a "pillar to organise around and in the process led to new organisations forming and strengthened old ones" (Willan cited in De Waal, 2006:42). In these contexts, civil society mobilisation has taken the form of self-organised social movements to tackle areas such as discrimination and stigma against HIV-positive people (Christian Aid, 2007).

Though research on civil society responses to HIV/AIDS is sparse, the focus on prevention documented in this section as well as evidence of community mobilisation around stigmatisation of victims of AIDS sits somewhat at odds with global responses that are more focused on AIDS control through curative practice and uptake of drug-based treatments. It would seem that there is a strong case for finding ways to bridge the gap by incorporating civil society perspectives more centrally into global HIV/AIDS policy. How might this be achieved?

Village families in Nigeria wait in line for HIV/AIDS voluntary counselling.

The West Africa Project to Combat AIDS and STI in Ghana, supported by the Ghana Ministry of Health and funded by CIDA-Canada, is located in the Osu neighborhood of Accra, the capital city.



How can HIV/AIDS Policy Become more Inclusive of Local Civil Society Voice?

Finding ways to incorporate civil society perspectives into national level HIV strategy and decision making is a major challenge. This would require moving away from welfarist approaches based on treatment to incorporate approaches based on the values of citizenship. A citizenship approach to HIV/AIDS grounded in the realities of local civil society would reframe the global HIV/AIDS debate within a broader context of the fragmentation of public health services. For example, it would speak out about the effects of skewed provision and rationing of services creating distortions between different socioeconomic groups in terms of access to good quality health care. It would also reveal the disconnects between global responses and dominant paradigms focused on treatment and local responses that are more focused on preventive care. This would shift the analysis to focusing on the longer-term and bottom-up strategies as to what has been known to work at local level rather than on short-term measurable results and outputs favoured by policies such as aid harmonisation, that disguise these underlying structural inequalities that have resulted from public health reform through global restructuring.

In terms of specific recommendations, INGOs need to exert pressure on their governments to critically appraise vertical programmes in the health sector that are focused on management of disease in urban settings. This would include adoption of a broader public health approach covering all regions of a country. There is also a need to gather meaningful data that is not simply based on curative practice and uptake of drug treatments. Further, participation of civil society in decision making about all aspects of public health has the potential to enhance the relevance of healthcare services to citizens in African countries and beyond. Delivery of health services thus needs to systemically include the perspectives of the users they purport to serve. This points to the need for those engaged in delivery of health services to enter into dialogue with communities and their representatives with a view to routinely integrating civil society voice into national level HIV strategy and decision making practice.

More broadly, lobbying governments to make the aid harmonisation agenda more inclusive of civil society voice is necessary for ripple effects to be felt and incorporated into global HIV/AIDS policy.

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