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AIDS, Citizenship and Global Funding: A Gambian Case Study

Rebecca Cassidy and Melissa Leach
May 2009



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Summary

Making sense of an HIV-positive diagnosis is often a struggle. Across Africa this is mediated by a new globalism in public health; the last decade has seen an array of new international initiatives and funding mechanisms. These dimensions of governance exemplify, in the health sector, an intensified move away from forms of authority based on the pre-eminence of nation states in global arenas, towards an array of new arrangements including global public-private-philanthropic partnerships. This Gambian case study unpicks the picture of an emergent 'therapeutic citizenship' (Nguyen 2005) in this context – of condom demonstrations and public disclosures – looking to the strands of authority and governance linked to an epistemic structure initiated by the Global Fund, but that works through a complex web of other organisations and agencies. This suggests that in Gambia in the period up to the end of 2006, the focus of this paper, a local-global axis which constructed HIV related problems, solutions and related notions of identity and political affiliation had come into being. For people living with HIV in the Gambia, making claims based on their status in this field has been problematic, and their ability to shape proactively what goes on and assert their felt needs often rather limited.

Keywords: HIV and AIDS; treatment, antiretrovirals (ARVs); support groups; identities; citizenship; global fund; NGOs; intermediation; The Gambia.

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Local Global Working Group preface

Working paper series on Citizen Engagements in a Globalising World

Around the world, globalisation, changes in governance and emerging transnational social movements are creating new spaces and opportunities for citizen engagement. Indeed, some would argue that citizenship itself is being de-linked from territorial boundaries, as power is becoming more multi-layered and multi-scaled, and governance increasingly involves both state and non-state actors, which often are transnational.

One of the research programmes of the Development Research Centre on Citizenship, Participation and Accountability, the Working Group on Citizen Engagements in a Globalising World explores the significance of these changes to poor and disenfranchised citizens. In particular, the group's work explores how the diffusion of power and governance resulting from globalisation gives rise to new meanings and identities of citizenship and new forms and formations of citizen action. The research programme is asking questions across local-national-regional scales related to

- The dynamics of mobilisation, paying particular attention to new forms and tensions of alliance-building and claim-making;
- The politics of intermediation around representation, legitimacy, accountability;
- The politics of knowledge around framing issues, the power to frame, dynamics of contestation across forms of expertise and ways of knowing; and
- The dynamics and processes of inclusion and exclusion to examine who gains and who loses.

The group's work is a unique contribution to a vast literature on transnational citizen action in the way in which each project examines the vertical links from the local to the global from a citizen's perspective, looking up and out from the site of everyday struggles. And while much normative and conceptual literature examines the concept of global citizenship, few studies of the theme are actually grounded in empirical study of concrete cases that illustrate how global reconfigurations of power affect citizens' own perceptions of their rights and how to claim them.

The group is made up of 15 researchers carrying out field projects in India, South Africa, Nigeria, Philippines, Kenya, The Gambia, Brazil and South Africa, as well as other cross-national projects in Latin America and Africa. The projects examine new forms of citizen engagement across a number of sectors, including the environment, trade, education, livelihoods, health and HIV/AIDS work and occupational disease, agriculture and land – and across different types of engagement, ranging from transnational campaigns and social movements, to participation of citizens in new institutionally designed fora.

The working papers in this series on Citizen Engagements in a Globalising World will be available on the Citizenship DRC website www.drc-citizenship.org, as they are completed. The Citizenship DRC is funded by the UK's Department for International Development.

Acronyms

| | |
|----------|-------------------------------------------------------------------|
| ART | Anti-Retro-viral Treatment |
| ARV | Anti-Retro-Viral |
| CBO | Community Based Organisation |
| CCM | Country Coordinating Mechanism |
| CCP | Coordinated Country Proposal |
| CCSI | Community and Civil Society Initiatives |
| CSO | Civil Society Organisation |
| DAC/MAC | Divisional/Municipal AIDS Committee |
| GF | The Global Fund to Fight AIDs, Tuberculosis and Malaria |
| GIPA | greater involvement of people with AIDS |
| HARRP | HIV/AIDS Rapid Response Project |
| HIV/AIDS | Human Immunodeficiency Virus/ Acquired Immune Deficiency Syndrome |
| HIV-TB | Human Immuno-suppressive Virus – Tuberculosis |
| IEC | Information, Education and Communication |
| INGO | international non-governmental organisation |
| MAP | Multi-Country AIDS Program |
| MRC | Medical Research Council |
| NAC | National AIDS Committee |
| NACP | National AIDS Control Programme |
| NAS | National AIDS Secretariat |
| NGO | non-governmental organisation |
| PEPFAR | (US) President’s Emergency Plan for AIDS Relief |
| PMCT | Prevention of Mother-to-Child Transmission |
| PPTCT | Prevention of Parent of Child Transmission |
| PR | Principal Recipient |
| SR | sub-recipient |
| STI | sexually transmitted infections |
| UNDP | United Nations Development Program |
| VCT | Voluntary Counselling and Testing |
| WHO | World Health Organization |

1 Introduction

The early twentyfirst century is witnessing a new era of globalism in public health. Driven both by moral concerns with poverty and disease in poorer countries of the South, and by Northern self-interest and mutual concern in an interdependent world of mobile people and microbes, the last decade has seen an array of new international initiatives and funding mechanisms. These dimensions of governance exemplify, in the health sector, a move away from forms of authority based on the pre-eminence of nation states. While this in itself is not new – global health having always relied to some extent on non-statist forms of authority, with international organisations such as the World Health Organisation overriding sovereignty in the name of claimed universal goals of disease eradication and prevention (see for example White 2005) – what is emerging today appears different in several important respects. First, the sheer size, scope and resources of the health programmes concerned. Second, the predominance of private, philanthropic and hybrid public-private arrangements, rather than international ones accountable to member states. And third, the moral authority that health programmes can now exert in a globalised world of mobile people and microbes, where fears of epidemic spread abound (see Dry 2008).

Nowhere is this particular kind of globalism more obvious than in relation to HIV and AIDS, where to cope with what is seen as an emergency epidemic requiring rapid mobilisation of resources, the global community has established three new funding mechanisms which are shaping programmes around the world: the Global Fund to Fight AIDS, Tuberculosis and Malaria (the Global Fund); the US President's Emergency Plan for AIDS Relief (PEPFAR); and the World Bank's Multi-Country AIDS Program (MAP). Together, these three funders now provide the majority (57 per cent in 2004) of all donor resources to combat HIV and AIDS (Bernstein and Sessions 2007). To date, the Global Fund alone has committed US\$ 7.7 billion in 136 countries (www.theglobalfund.org/en/).

Focusing on the Global Fund's operations in African settings, and through a particular focus on the case of The Gambia,¹ this paper explores the implications of such new global public health, and its politics, for citizenship. It asks how such globalised initiatives are being experienced in local settings, what new spaces for citizen engagement are being forged, and how such engagement is unfolding in practice – through what opportunities, constraints and forms of mediation. Exploring these questions, we suggest, requires attention to both material and epistemological dimensions. As we shall explore, initiatives such as The Global Fund (GF) are unleashing both a new political economy of resource allocation, and a new politics of knowledge – and both have profound implications for forms and practices of local-global citizen engagement.

1 This paper looks explicitly at the period up to the end of 2006. For reasons beyond the scope of this paper to discuss, events since January 2007 concerning AIDS treatment in The Gambia cannot be represented here, although they show a quite different picture. Thus this paper must be read as a recent historical account of a particular moment in the interactions between different actors in the HIV and AIDS arena.

The case of The Gambia provides a lens to illuminate these questions. For while its AIDS story, while terrible for those living with it, is not Africa's most dramatic (HIV infection rates currently remain below 5 per cent),² these claims and structures can be seen clearly as part of a global politics of knowledge and authority around health and disease. These construct HIV related problems, solutions and related notions of identity and political affiliation in particular ways. These connect the local and the global in a vertical spiral or vortex that whirls citizens up into it – although as we shall show, the capacity for people living with HIV to shape proactively what goes on this spiral has been rather limited.

This case provides an opportunity to reflect further on what citizenship is coming to mean in the new context of health globalism. In this vein, Robins (2005, 2006) emphasises the potential of health-related activism, strong illness identities and the scarcity of treatment to shape new subjectivities and types of health/biological citizenship. Nguyen (2005), in analysing HIV activism in Burkina Faso, describes a 'biopolitical citizenship' that he calls 'therapeutic citizenship' which encompasses 'claims made on a global social order on the basis of a therapeutic predicament' (2005: 126). Nguyen's emphasis on the broader industry that has arisen around HIV issues, the heterogeneous conglomeration of different actors and the activation of global networks suggests the emergence of forms of civil society mobilisation whose alliances transcend national boundaries and connect local groups to key global players and knowledge. He argues that HIV has been able to bring together a range of different phenomena, from condom demonstrations and CD4 counts to sexual empowerment and an ethic of sexual responsibility and compliance with drug regimes, into a stable, worldwide formation. These new global networks have helped to produce a form of therapeutic citizenship based on being HIV positive (biological) together with certain (political) claims to rights (i.e. access to treatment) and 'ethical projects' – ways of integrating being HIV positive into a moral order. With these networks come chains of expertise and so intermediaries, from local and international NGOs to parts of state organisations, who act with or on behalf of people living with HIV and enable them to tap into income streams and access programmes.

In exploring the experiences and practices of support groups accessing anti-retroviral treatment in The Gambia, we find that these arguments about emergent therapeutic citizenships apply to some extent. For people living with HIV, the support groups do in some ways appear as sites of active therapeutic citizenship, negotiated through a range of mediating political and NGO structures. Yet in the Gambian political-economic context of extreme poverty and daily struggle to get by, we find that basic livelihood concerns and material support often trump therapy as motivations for support group membership. We find that people's adoption of biomedically-shaped HIV-positive identities and AIDS-related 'sick roles' is contingent and fragile, negotiated with other forms of knowledge, subject-positions and worries about disclosure. And we find that in a country with

2 New Sentinel Surveillance data, which has not been published – in fact suppressed – gives prevalence rates of 2.8 per cent for HIV-1, and 1.1 for HIV-2. This is a rise from the last survey which showed a reduction in both to below 2 per cent, but is probably a more realistic estimate given that it tallies with 4 per cent in Senegal.

a longstanding history of mediation by political and NGO structures, people have rather little power to shape their relationships with them. Rather than the image of active, treatment rights-claiming, therapeutic citizens, then, what we see is a less-empowered conformity to global discourses and procedures as a route to particular sorts of 'getting by'.

We begin by sketching some key features of the Global Fund's operation and the debate that has emerged around citizen and civil society engagement with it in African settings, before turning to the experiences of the support group members and others involved in the 'AIDS industry' in the Gambia in the pre-2007 period. In conclusion, we reflect on constructed citizenship and opportunities for local-global engagement.

2 The Global Fund in a world of international health funding

The GF is part of a new generation of global philanthropy in the health and broader science, technology and development fields, and a new generation of global public-private partnerships. In material terms, such global initiatives aim primarily to channel funds but in so doing contribute to the building of political-economic and authority structures geared to doing this 'efficiently' and 'appropriately' – as defined by the neoliberal and business-oriented models of this genre of development aid. Initiatives such as the GF also have an epistemic influence; framed by particular perspectives and forms of knowledge concerning the nature of the problem, and hence the required solution, they also help to put such framings into broader play. Yet such power-knowledge relationships through governmentality are always dynamic and negotiated to some degree, and shaped strongly by the structures and practices of mediation of global and local forms. In this section we outline some of the key processes through which such governmentality appears to be playing out through broad experiences with the GF in a variety of African settings, exploring particularly how far GF initiatives are responding to the material and knowledge claims of citizens.

The GF is interesting in this respect because it explicitly presents itself not as a top-down global mechanism, but as 'uniquely' locally responsive. The Fund defines itself as offering an innovative approach to international health financing based on partnership between governments, civil society, the private sector and affected communities. As we outline below, it works in novel ways that claim to give civil society and grassroots groups an unprecedented ability to make claims that meet their needs, through representative participation in a country coordination and partnership mechanism and – in principle – through direct civil society applications to the Fund. Yet in practice, the extent to which citizens have been able to stake claims on the GF effectively in relation to state authority structures, or to by-pass them, has been highly variable.

Since 2004, the Global Fund, along with PEPFAR, and the World Bank's MAP have been providing large volumes of new money for HIV programmes. These new resources provided by 'the big three' funders represent a huge increase in

funds at the country-level. In Uganda and Ethiopia, for instance, once money began flowing from all three funders in 2004, the amount quickly approached, and by 2005 had exceeded, the governments' 2003 budgets for the entire health sector (Bernstein and Sessions 2007). The scale of resources, and their dispersal through vertical, disease-focused programmes, has given rise to heated debate about the extent to which the globally-structured 'AIDS industry' may be undermining national and local health systems and their broader priorities.

The funding and operating structures of global HIV initiatives, both in principle and in practice, shape how these global-national-local relationships play out. In the case of the GF, the founding principles state that 'The Fund is a financial instrument, not an implementing entity' (Global Fund 2002). In keeping with this philosophy, the GF claims a 'unique model' in which it has no in-country presence or technical assistance expertise. Instead, it aims to operate within a broader network of partners, whereby its funding is complemented by the activities, expertise and resources of national governments, NGOs, civil society organisations, and private sector partners. The claim to uniqueness may be questioned given the ubiquity of partnership models and direct budget support amongst development aid donors generally today. Rather, what appears more distinctive is the set of structures which the GF sets up in-country in order to 'do partnership'.

Thus in this model money contributed to the Global Fund (by governments, philanthropists, donor agencies, the private sector, and public donations – such as through the RED campaign) is held in trust in an interest-bearing account at the World Bank, until the Global Fund requests funds to make a grant in-country. The preferred mechanism is for a single Co-ordinated Country Proposal (CCP) to come from the national level, through a Country Co-ordinating Mechanism (CCM) which becomes the focus for programme accountability. The CCM is the key, novel organisational model at the heart of the GF's framework, including its claims for civil society involvement. As the GF Framework Document (Global Fund 2002) states, the CCM 'should include broad representation from governments, NGOs, civil society, multilateral and bilateral agencies and the private sector. The mechanism should be at the highest national level responsible for national multi-partner and multi-sectoral development planning. It should preferably be an already existing body. If no appropriate coordinating body exists, a new mechanism will need to be established'. In principle, this mandates civil society representation and 'ownership' as a condition for programme funding – and demands establishment of a structure to ensure this where none might have existed before. The framework document also allows the possibility – in political contexts where governments are illegitimate, in conflict or acting to suppress civil society activity – of forging funding partnerships directly with civil society.

The other key structure in the GF's funding framework is the Principal Recipient of a country grant. This is the organisation to which funds are channelled, and which carries out disbursement to sub-recipients as identified in the CCP. Principal Recipients are typically a government ministry such as the Ministry of Health, or a government agency such as a National AIDS Council. In some cases, a Principal Recipient may be a non-governmental organisation or a UN agency. When sub-grants are made, the Principal Recipient remains responsible for reporting to the Global Fund on the use of funding.

In theory, these principles give unprecedented scope for civil society groupings both to lever funds for their own activities (as principal or sub-recipients), and to shape country strategies for dealing with HIV and AIDS. Government representatives have sometimes critiqued the CCM model for this very reason (Brugha 2005). However, in practice experience has been more varied. For instance Senegal was an early model for the GF's mechanisms and received significant new funds from the GF and MAP in 2002. However as the country attempted to scale up its response to HIV, significant concerns arose about the lack of a coordinated national strategy and, especially, the marginalisation of civil society – to the extent that the GF in 2005 threatened to withdraw funding. In the Senegalese case, the situation was shifted by a coordinated response from NGOs, who created a 'watchdog' organisation (the Observatoire de la Reponse au VIH/SIDA au Senegal), which helped to push for a designated civil society part to the country's 2005 GF proposal, and for a civil society Principal Recipient, the NGO ANCS. It is argued that as an NGO, ANCS is closer to communities, more flexible, and able to disburse funds more effectively to people living with HIV (Alliance 2007).

In other country settings, too, comparative tracking studies have begun to indicate a range of problems in attempting to operate effective CCM partnerships. Thus in Uganda, Tanzania, Zambia and Mozambique (Brugha 2005), CCM forums revealed major tensions between government bodies and between government and civil society over the distribution and use of new funds for HIV control programmes. These tensions were not caused by (and had preceded) the Fund, but were exposed and heightened by the Global Fund process. All four countries encountered, to varying degrees, similar problems around the ineffective representation and participation of civil society constituencies, and a dominance of high-level line ministry representation, reflecting the high political stakes of the GF process.³

Civil society critique – for instance in Mozambique and Uganda – has also turned on the dominance of government bodies as principal recipients, linked to tendencies for them to be the main beneficiaries of GF resources (Brugha 2005). In Uganda, for example, civil society organisations were by 2004 highly vocal in their critique both of government and of the GF in this respect. In Zambia, the appointments of an NGO and a faith-based body as PRs were seen as addressing a fundamental concern to see a significant proportion of Global Fund resources channelled through non-government bodies, in keeping with the claimed spirit of the Global Fund approach.

As Brugha (2005) describes, such struggles and tensions around the meaning of partnership in GF processes revealed deeper tensions: around the relative importance of plurality amongst multiple stakeholders, versus coordinated stewardship by government, and more fundamentally, ideological questions around the legitimacy and role of government in a world of globalised networks and partnerships involving civil society organisations.

3 This is despite the fact that in practice line ministry representation at CCM meetings was often too low to ensure effective momentum in mainstreaming and inter-sectoral commitment around HIV activities (Brugha 2005).

Meanwhile, guidance and guidelines to CCMs from the Global Fund for dealing with such tensions has often come late, if at all, and has paid little heed to the contextual power dynamics that caused them. Nor have processes been established for brokering agreement amongst the different stakeholders on their respective roles and responsibilities.

Most GF tracking studies have stopped at the level of the Principal Recipient, and do not characterise or disaggregate within 'civil society' as recipients of GF resources. Others have, however, pointed to the low proportion of HIV funding from all sources that reaches community groups (Foster 2005) – in the case of the GF despite a stated commitment to reaching affected communities. A recent study of Lesotho, Malawi and Swaziland finds that only 10 per cent of Civil Society Organisations (including NGOs and community-based organisations) receive about 73 per cent of the funding to civil society (Birdsall and Kelly 2007). A very small proportion of community-based and grassroots groups, such as groups of people living with HIV, are thus receiving funding. More significantly, two-thirds of all CSO recipients of support receive it through intermediary NGOs or umbrella structures and programmes, rather than directly from vertical funders such as the GF. This suggests the key role of intermediary organisations in shaping access to resources. Indeed the fastest growth in scaling up funding to civil society has occurred amongst intermediaries, and their role has been key in mobilising other civil society organisations, including grassroots and community groups – to take up HIV work (Birdsall and Kelly 2007).

Birdsall and Kelly (2007: 12) draw attention to how 'Centralised vertical programmes and channels ... are criss-crossed at all levels by a flurry of smaller-scale activity that may or may not be linked to the official response framework.' Insightfully, they suggest that from very heterogeneous roots, those activities that do become linked tend to group around a relatively standard, ordered set of interventions. These are situated along the continuum from prevention through to care and support, treatment and rights, and are clustered under broad headings: prevention (VCT, behaviour change communication, prevention of mother-to-child transmission (PMTCT), activities targeted at high risk and vulnerable groups, control of sexually transmitted infections (STIs, blood safety, infection control, workplace interventions), care and support (home-based care, support groups, networks and associations of people living with HIV, treatment of opportunistic infections, nutrition, psychosocial support), treatment (ART), impact mitigation (support for orphans and vulnerable children, income-generation projects, food security) and rights (anti-stigma and discrimination, leadership, human rights, and the 'greater involvement of people with AIDS' (GIPA) principles). Many national plans – and proposals to international bodies such as the GF – contain these standard elements, despite widely varying epidemiological and socio-political contexts. As they put it,

The comprehensive response framework seems to leave little space for anything short of addressing all elements simultaneously. This is strengthened by the fact that core elements of these responses are increasingly linked into global targets – the '3 by 5 campaign' and the

campaign for universal access to prevention and treatment – which are structured around the same intervention categories.

(Birdsall and Kelly 2007: 16)

Put another way, the global AIDS funding industry is helping to put into play an epistemological standardisation – a standard set of solutions, responding to a standardised set of framings of the problem that link biomedical notions to what have become globalised received wisdoms about HIV and AIDS. These globalised framings do, of course, contain minor variations and contestations, responding to the diverse positions, histories and ideologies of different agencies. Comparing the framings offered by the GF, MAP, PEPFAR and others in this respect could be interesting, though beyond the scope of this paper. Nevertheless, these are largely variations within a broad, dominant contemporary framing of AIDS as an exceptional epidemic requiring exceptional responses which emphasise biomedical solutions and individual rights (see Edstrom 2008).

Brugha (2005) point out a competitive dynamic within countries' engagements with the GF process that can be seen to perpetuate such globalised constructions. Thus in many cases CCMs have become focused on trying to identify what the Global Fund was likely to fund, rather than what internal discussion suggested their countries might need. In the case of Uganda, for instance, when early proposals focusing on country priorities for system-wide strengthening were rejected, the CCM reverted to disease-specific proposals based on the belief that these were more likely to be funded. A focus on proposals that directly tackled disease – such as ART – also reflected perceptions that the GF would be more likely to respond to these because they could be expected to lead to impact indicators of the kind that donors liked. This in turn responds to the mantra regularly repeated by the GF's Executive Director: that the GF's mission is to 'raise it, spend it, prove it,' emphasising the drive to raise large sums of money, to disburse it quickly, and then to demonstrate concrete results at the country-level.

Structures of funding access, globally and in-country, can thus be seen to interplay with an epistemological standardisation of problem-and solution interpretation around HIV. The influence of such global framing, it can be argued, often comes to extend beyond those organisations actually receiving funding through globalised vertical programmes and the intermediary organisations that shape access to them. A wider global epistemic community (Haas 1992) or culture (Knorr-Cetina 1999) is emerging around HIV through the array of global networks and forms of knowledge exchange that these programmes are part of. As Nguyen (2005) shows, this has come to include citizens' networks and enwraps forms of therapeutic citizenship constructed around particular, globalised ideas of what it means to be HIV-positive. While specific struggles may be taking place over who receives or fails to receive funding, and over precise programme priorities, much of this debate and struggle is now taking place only as minor bit-parts within the broader epistemological play that is AIDS globalism.

As we now go on to explore in the next section, in the Gambian situation, such tensions – and their playing out only within a broad epistemological context in which HIV and AIDS are seen as biomedically-defined problems amenable to certain sorts of response – are evident.

3 Global AIDS funding in The Gambia

3.1 The introduction of global HIV and AIDS treatment programmes

The first case of HIV in The Gambia was identified in May 1986; the Director of the British-funded Medical Research Council laboratories (MRC), then working as a physician, remembers carrying the samples back to the UK to run the tests. In 1987 the then Ministry of Health, Labour and Social Welfare established the National AIDS Control Programme (NACP), and parliament also approved the foundation of an advisory committee, the National AIDS Committee (NAC). The response at this time was strongly led by medical and public-health perspectives and predominantly focused on Information, Education and Communication (IEC) activities. Funding came from WHO's Global AIDS Programme. In 1990 the first five year Development Plan, again mainly WHO and UNDP sponsored, was established. However aid streams were cancelled at the time of the coup on 22 July 1994, when the APRC and the current president took power.

In 1995 a first attempt was made to embark on a more integrated, multi-sectoral response to HIV – again funded by UNDP and WHO when the NAC was reconstituted. As in many other countries at this time, it was realised that 'A more targeted and intensified response is required to create awareness, provide treatment, care and support as well as mitigate the impact of the disease on individuals, families, communities and the nation as a whole.⁴ Many elements of what were becoming standardised global packages began to be put in place, although interventions taking a bottom-up community perspective – such as the participatory learning and action interventions of Stepping Stones – were also evident at this time.

The year 2000 was a landmark for HIV programming in The Gambia. An application was submitted, and approved in September, for MAP funding from the World Bank. The Gambia was among the first countries to access HIV/AIDS Rapid Response Project Funding (HARRP). The programme – providing US\$15 million – came into effect on 31 July 2001. The first National AIDS Forum was also organised in 2000, held at the Kairaba Hotel on 1 November. Notably the president attended this event, and gave the fight against HIV his, and his government's, full support, stating that no civil servant would be sacked based on their HIV status:

The HARRP supported the creation of the National AIDS Council which is chaired by the President His Excellency Dr. Yahya A.J.J. Jammeh. The National AIDS Secretariat (NAS) was also created to coordinate the response and serve as the technical arm of the NAC. At the decentralised levels the NAS created Divisional/Municipal AIDS Committees (DAC/MAC). The

4 Quotes in this section come from interviews and prepared statements from Gambians with long experience of working on HIV in the Gambia, working within various organisations as well as government.

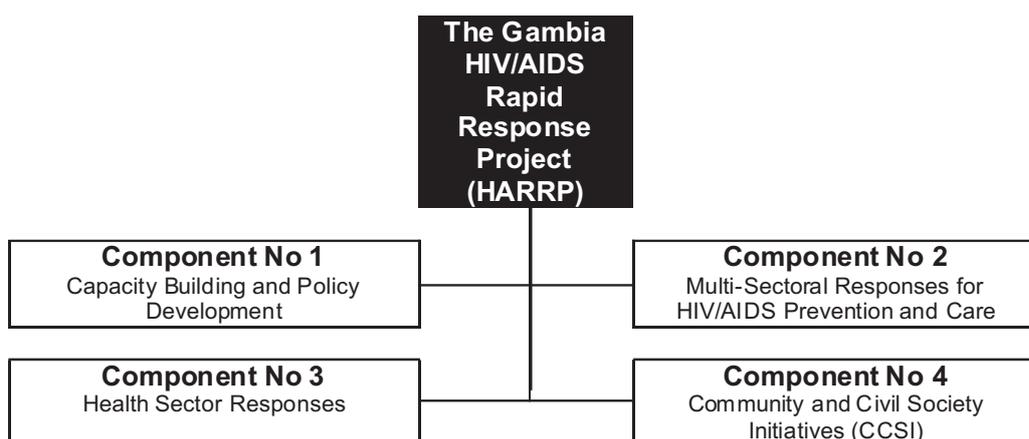
membership of both the NAC and DAC/MAC was multi-sectoral with the view to enshrining the key strategies of cross-sectoral approach to the national response to HIV/AIDS.

Some describe the HARRP money as ‘seed money’ for the main Global Fund grant; although unlike Global Fund grants it requires repayment with interest. In The Gambia, it was HARRP funding that allowed an HIV treatment programme to get started, and to get some patients onto ARVs – those who were waiting at the main two operational treatment centres. The advent of ART in the Gambia, as in other contexts, radically altered the relationship between patients and treatment centres, as one health worker reflected:

The treatment programme? This clinic is exceptional, in the country. I think so. Generally, looking at those who are on, who started ARVs up to now, I am contented. I remember some people who even gave up coming to this clinic, because they thought, I mean, they will not have any benefit, coming to this clinic, is only coming, bleeding, you know? Some of them don't understand. They are coming here, only sucking up their blood, getting only small drugs. It's not beneficial. I know of people who advocated going to Senegal to get drugs. They are now with us. They are happy.

The HAARP programme had four main streams: institutional capacity; multi-sectoral responses; health sector response – including some ARV treatment as well as VCT, PTCT, STI treatment, training and strengthening HIV-TB links; and community and civil society initiatives.

Figure 3.1 HARRP components



Source: The Gambia HIV/AIDS Rapid Response Project Borrower's Implementation Completion and Results Report, December 2006

Although there were problems with implementation, it is arguable that these funds enabled the setting of a broad agenda for HIV work in the country. They also enabled support groups for people living with HIV to come together for the first time:

NAS, through HARRP, lead with resources, and set the agenda for collaboration with civil society, from CBOs to NGOs to the UN ... NAS through HARRP created an environment, especially in political involvement. Senior government staff were able to talk on HIV issues, the president called for VCT, and an end to stigma.

HARRP put HIV at the forefront of the development movement, it was a wake up call at all levels ... resources were made available to organisations that would've never had access before, and would never have worked on HIV. Santa Yalla [support society] came up, as they had resources, and also others had resources to do things with Santa Yalla.

HARRP funding allowed for the setting up of NAS, and the writing of the first strategic plan for the Gambia, and so enabled the country to access Global Fund financing. The Global Fund grant, of US\$14million, successfully applied for in Round Three, came into effect in 2004, and took over ARV treatment provision as planned. HAARP prevention programmes ran until the end of the life of the loan, 21 December 2006.⁵ It was planned that these prevention activities would also be taken over by further future successful applications to the Global Fund, as prevention programmes were not a major component of the original Round Three grant. This has not happened. Applications to both Rounds Five and Six have failed, with some strong criticism from the Global Fund of the way in which the applications were structured, and so with much internal criticism in The Gambia for those involved. However, under the original GF grant, HIV programmes in The Gambia have continued to grow, with six ARV treatment centres⁶ now operating around the country, as well as 24 VCT centres, and 17 PPTCT sites.

3.2 Material dimensions in practice

We now describe some of the material ways in which HARRP and GF funding mechanisms, and the administrative bodies involved in dispersal and project implementation, have worked in practice 'on the ground'. We also consider how these processes have been viewed and experienced from the perspective of people living with HIV and their support groups.

Prior to the arrival of massive international funding for HIV and AIDS activities, the NACP – the National AIDS Control Programme – within the Ministry of Health, had run all prevention activities, as well as the PPTCT programme,⁷ which had already

5 HARRP had been due to finish in July 2005, but was extended until the December of the following year.

6 Upcountry Treatment Centres in Bwiam, Farafenni, Bansang and Basse have been beset with problems. Farafenni had one patient start treatment who later died. Basse is run by a Faith-based NGO, and is generally the best centre. However, they have never had a doctor to prescribe drugs and present cases to the national eligibility committee (in Banjul), patients and staff were visiting the doctor in Bansang, however there is now no physician here either. These treatment centres continue to be operational with the continued support of NGOs (in Basse and here in Kombo/Western Division) and the dedication of both their staff and, especially, patients to travel the length of the country to centres in Brikama, Banjul or Fajara to collect drugs for themselves and others.

been working out of clinics and health centres since 2001. The NACP's prevention work was predominantly IEC – Information, Education and Communication – activities; posters and billboards, TV adverts, and sensitisation events in collaboration with organisations and INGOs working on HIV, as well as the main two patient support groups, attached to the main two HIV clinics, the only ones operational at this time.

Once it became clear that large volumes of money would be arriving in The Gambia for HIV programmes, NAS – the National AIDS Secretariat – a second, and some would argue parallel, division was set up to take charge. NAS was never formally constituted however, and was funded not as a government department, but with HAARP money. While the NACP works under the Ministry of Health, and so under the authority of the Secretary of State for Health, NAS was created in the office of the president. However, its political involvement was 'cosmetic', or 'symbolic, only at the level of making statements, any actual interest was lacking'. For example, although NAS was officially under the control of the Secretary General, he never once visited the office.

In theory, NAS should have been an administrative body for global AIDS resources (Principal Recipient – PR), and NACP an implementing partner – one of many sub-recipients (SRs) – to whom funds were released. In practice these boundaries blurred as NAS implemented its own projects. There has always been a certain amount of resentment and jealousy from NACP, and the Ministry of Health as a whole, towards NAS, perceiving that NAS usurped NACP's position once the cash arrived. NAS had its own internal problems, with what many characterise as 'weak' leadership, and staffing problems; NAS was still recruiting, finding offices and procuring basic equipment until the end of 2003. Many people have also complained that NAS has been disorganised and inefficient, failing to release funds on time. Particularly for smaller organisations this can have drastic effects, as they do not have the funds to begin programmes or pay staff while waiting for payments to arrive. At the divisional and local level NAS funds were also divisive, as they led to some staff within the health system receiving salary supplements and motorbikes, while others did not. Some of these other staff refused to see 'their' patients – why should they, when they were not getting the extra benefits? In practice this meant that VCT was unavailable at designated centres when the 'correct' person was not around, or that mothers coming for checkups or drugs under the PTCT programme were sent away empty handed by those who had not received salary top-ups. Staff perceptions of who was and who wasn't receiving extra money were often wildly inaccurate across all treatment centres, but the extent of the rumours and discussion indicates the divisiveness of these payments.

With the arrival of the HAARP money, NAS became extremely rich, as did many other people and organisations. Indeed, there was always a problem spending the HAARP money. At one point an international consultant was contracted to give

7 Prevention of Parent to Child Transmission, also previously called PMTCT programmes. However, Prevention of Mother to Child Transmission places the focus squarely on the mother, whereas PPTCT tries to involve men and to shift the blame and responsibility away from a women-only focus.

advice on how to spend it faster. Across The Gambia emerged a situation in which more or less anyone – youth groups, women’s *kafoo*,⁸ or any kind of local organisation, could apply to their DAC/MAC to access funds. This appeared, for a short while, to represent genuine ‘grassroots’ civil society access to global AIDS funding. Yet many new organisations formed at this time, only to be disbanded shortly afterwards. The majority of the projects were one-off ‘sensitisations’, some of which were well organised and well attended: football matches and fun-runs as well as dramas and so on, with t-shirts, slogans, and speeches. Others seemingly did not exist at all. Millions of Dalasi were spent in this way, and a predominant view – ‘there is money in AIDS’ – took root. For those who knew who and where to ask, and how, this was certainly the case. People were paid per diems to take part in events and discussions, in order to get the money out of the door. And expectations rose around how, and how much, HIV-related income could be made. The final report for the HARRP Project admits these shortcomings, and lists under ‘lessons learnt’:

The passion for the fight against HIV/AIDS was mixed. A number of partners saw the HARRP as a money making enterprise hence the submission of substandard proposals. This invariably means that the screening and review process of proposals take a much longer time than necessary. In some instances, the rejection of proposals led to dissent by some of applicants.

One striking example of this is the National Assembly Members’ proposal, which was refused. They requested US\$250,000 for one week of activities, visiting various sites around the country. When this was refused the assembly members blamed NAS and made them a target, even attacking NAS in a public forum when the National Assembly met. As a result of this and other events NAS became a target within the government, and the focus of much jealousy over the money they were seen to be sitting on. There was also some anger from other agencies and organisations. Even the UN system came to be ‘redundant’ and ‘invisible’ during this time, as its grants and projects were dwarfed by the spending power of HARRP.

After this initial period, some attempts were made to control what kind of programmes received funds. By late 2006 most people at all levels spoke frankly about the mistakes that had been made. People in the patients’ support groups, in particular, felt that while they had been supported to some extent, a great deal of the money that they knew had arrived in the country ‘for us’ had been wasted, rather than given to those directly affected by HIV, and in need of assistance. There was a feeling that many people had benefited from getting involved in HIV work in a very superficial and self-interested way, seen in the big cars and offices that some had gained, and that nothing lasting had been done: ‘they just ate the money’.

When I hear Global Fund, I don’t even think of [this clinic], because I’m not seeing it. No, I’m not seeing it. When somebody talks of Global Fund I think of NAS ... I always think that the Global Fund is not being properly being

8 Peer group organisations, often age or gender-based, that play central roles in Gambian communities.

utilised. I thought the Global Fund was here for HIV patients. It's not only HIV patients who are benefiting from it. Maybe with the [clinic] it's ok, because the without the Global Fund the drugs could not come. And school fees.

Health Care Worker, HIV Clinic

As the life of the loan came to an end, in December 2006, it became clear that the money could not be spent. Those in the support groups were aware that there was over a million dollars still remaining, which would be sent back when the project ended. Not only this, but NAS was still not officially constituted, and so would cease to exist, as would the funding they provided to support groups for their projects, centres, salaries, rent and running costs. For those in the support groups there was bitterness and resentment as they saw how they could use the money, and yet were told it could not be justified according to the original HAARP proposal aims and objectives. The insecurity felt by all was palpable; every day in groups or clinics people would discuss what would happen. Staff members in the Support Society lost their salaries for cooking and cleaning the centre, previously paid either direct from the HAARP or through intermediaries. NAS regional representatives who had worked on projects up-country for years expected their positions to continue, but as the final weeks arrived it became clear that the rest of the money would be returned, and they were called to Banjul for their final meeting. NAS offices closed around the country, although the main office, as Principal Recipient of the Global Fund Grant, continued to operate, although still not officially constituted as part of the government. Arguably such conceptions of appeals beyond the nation state build solidarity, as for example in South Africa. In this context though the question of access to treatment has never been an issue; with ARVs provided free through the GF programme. This negates the need for activism on the scale seen elsewhere, although HIV is not a 'normalised' chronic condition (Robins 2005).

Just after this the second refusal came from the Global Fund for the Round Six proposal, and the head of NAS was removed. Those within NAS at the time stress that too much was made of the unspent funds, which amounted to less than US\$200,000, while with the fall of the dollar in the final year an extra \$1million was added in foreign exchange gains to the total amount dispersed. But feelings ran high as people living with HIV, and in poverty, felt powerless to influence these massive flows of money, and yet were acutely aware of what was happening. As one support group member put it: 'How can they ask for more money with one hand, when they are giving it back unspent with the other? They know ... they talk to each other, the World Bank and the Global Fund' (group member, December 2006). Thus a transnational, and stateless, sense of entitlement to funding was widespread, with the World Bank (through HAARP) and the GF presenting themselves as duty bearers from whom these HIV-positive citizens in The Gambia could claim rights. However, these rights, seen in economic terms, were not played out or fulfilled as expected, and the failures easily attributable to those in-country agents through which these funders operate.

The Round Five proposal to the GF had included 45 partner organisations, running a variety of projects, including – still – a number of one-off sensitisations, trainings and events. The Global Fund rejected this proposal, citing these reasons, as well as a lack of coherence and vision. While there was some

disappointment, many felt that there was always next time, and after all, the HAARP project was still running. Those involved were not greatly surprised. The NAS office was frequently visited by people from organisations providing services and support as well as carrying out prevention activities and education, clutching budgets with massive provision for various items, all costed and set out to the maximum extent possible. The expectations of an HIV gravy-train were entrenched, and the feeling that you only had to ask widespread. For those involved in putting together the proposal this resulted in an impossible task – how to disappoint any of these organisations and their expectations? In the end all went in: everyone was included, but at the cost of the proposal being turned down.

The planning meetings for the GF Round Six proposal in the second half of 2006 were much more fraught. As the end of HAARP was in sight, many organisations and individuals, especially in the light of the previous refusal, were conscious that HIV might not be the guaranteed pay out they anticipated. Discussions around ‘gaps’, and looking to what was already funded elsewhere, put many organisations and individuals on the defensive, as their interests were suddenly in competition with others, and the importance of their programmes assessed rather than accepted.

The support groups, who already felt that ‘NAS treats us like children’ and controlled the activities they were allowed to apply for funding for, felt constricted, and left out. Those who did attend these meetings were included, although all discussion was in English, and some felt ill and left half way through. Some ‘corridor-talk’ seemed to assess this as inability to take part, based both on education levels and understanding of the processes, and interpreted illness as faked to disguise laziness and ignorance. However, it is the case that people from the support groups were invited to all these meetings, and set the specific task of looking at care and support programmes in group discussion. This consultation process was used to inform the writing of the proposal by consultants. How much this participation by the support groups was a tokenistic and cosmetic process, rather than a real opportunity to affect the final document, is open to conjecture. Tokenism is suggested by that fact that some organisations were invited to the first round of meetings, but not the second. Equally, submission deadlines for comments sometimes failed to tally with meeting times, implying that there was no intention of including them.

These tensions between individuals and organisations are exacerbated in The Gambia due to the relatively small population and tightly linked community. Gambians often tell you that ‘we are all family’; however, as in families, the small distances between people can be a barrier to good working relationships. Whereas the staff of NAS or other organisations would in another context not all be personally known to support society members, here this created an environment in which individual people as well as the organisations were seen to be responsible for what was seen by some as misuse of ‘our’ money. The project cars or improvements made to their homes by some staff were seen as illegitimate and pointed to as evidence of the failures of the ways in which the ‘AIDS industry’ was functioning.

In the end this proposal failed as well, and the CCM met to discuss what came next. It was decided that more time was needed to take stock, and particularly to get information together, to have an evidence base for Round Eight. Round Seven was seen to be too soon, and has now passed without The Gambia submitting an application.

The recent history of the GF in The Gambia, in practice, thus reveals a struggle between a globalism in HIV funding pitched to include and meet the claims of civil society including support groups, and elements of the state that sought to control the process. In the context of the enormous funding flows available, the material dimensions of this struggle – the perceived AIDS gravy train – have tended to be at the forefront. Yet people living with HIV have felt powerless to influence these large scale political-economic machinations.

The structures put in place by the GF to enhance participation and inclusion of ‘civil society’ in this context function to the benefit of NGOs and more established bodies. These organisations, able to act as SRs, take on the role of intermediaries for the beneficiaries of GF programmes – people living with HIV. Whereas some intermediaries can be said to coordinate and fund projects which could not have been organised by the support groups themselves, and in this fill a knowledge and experience gap which exists between the abilities and competencies of groups and their staff and the requirements of funders in terms of reporting and justification. In other cases there is a question to be asked as to whether these intermediary bodies simply increase the distance and difficulty for those at the sharp end seeking to access funds.

To the extent that people living with HIV have been invited to have a voice in GF processes in The Gambia, however (in)effective this has been, the support groups have been the main organisational form. Yet what does group membership mean in practice? What forms of representation are involved? And what are the material and epistemological implications of being in a group? It is to the dynamics of the groups and the extent to which membership implies a new form of therapeutic citizenship that we now turn.

4 Patient support groups and citizen engagement with the Global Fund

As indicated above, the HIV support groups in The Gambia emerged, and continue to be constituted, through a highly mediated process. It was in the context of global AIDS funding that they first began to appear. The setting up of the first support society in 2000, Santa Yalla, was facilitated by the Medical Research Council, with specific individuals – mainly physicians – taking an active part. There are now ten support groups and two national networks, one specifically for women with HIV, active in The Gambia. In line with the original set-up of the groups, the majority of members agreed to visit after referral by their doctor or counsellor, to the group affiliated with the clinic they attend. This link remains strong, and the new groups have been set up linked to the ARV-treatment centres up-country, the two newest groups are the first to be independent of this,

although they still link to clinics providing other HIV-related services and referral.⁹ The meanings and practices of group membership reveal an uneasy balance and set of tensions between needs and priorities felt by group members themselves and the expectations of donor, NGO and government 'partners' as to what such a citizens' group operating in a world of globalised HIV funding ought to be like.

The meanings of the groups from members' own perspectives are strongly shaped by Gambian daily realities of grinding poverty, as well as a social and gender context which tends to promote conformism and hierarchical interactions, responsibilities and obligations. This social context presents an immediate contrast with the assumptions of individual rights-claiming which underlie the image of 'therapeutic citizens' in contemporary AIDS globalism. The groups are formed of a wide variety of people, so that there sometimes seems to be little that ties them together – only a virus. However, at least in the urban and peri-urban areas,¹⁰ most of those who choose to join do so because they feel they need an alternative or additional social support network. Strong social bonds are formed within the group and for some, especially female members who spend days together in the centres with their children, they become a second home. Strong relationships form between members, and there has been one marriage. Among those who join are a disproportionate number of immigrants to The Gambia from neighbouring countries, recent migrants to urban areas, and others who for a variety of reasons feel they receive little support in their home environment – whether or not they have disclosed their HIV status. Those who attend regularly also know that 'if I don't come someone will call', and also provide transport to the clinic if they fall ill. This provides a reassuring link, especially for those who live alone in rented accommodation.

Membership is also predominantly from poorer sections of the population; there are no middle class members, and some have felt excluded by this, not wishing to associate themselves publicly with a group that only 'low class' people attend. Those who join and spend regular time with the groups value both the social and economic support they provide. The latter includes nutritional support packages, school fees and other benefits. Indeed the provision of food is a priority for many members. The original groups all provided a meal everyday and so nutritional support for people who often cannot afford to eat. Members also loan each other small amounts of money (although this can also create tension) and give gifts – the occasional chicken changes hands: 'I just wanted to give it to him'. Such gifts help people to keep each other going, or help to cope with the added financial burden of unexpected family ceremonies and so on. Group members stress these factors, as well as the fact that they can share information and learn about their condition both in official meetings and more importantly from each other. The groups, in these ways, provide a sense of community. Equally there are tensions

9 Although there is a strong link between clinics and the groups, due to the logistical and staffing problems experienced in up-country settings, there is a weaker link to be seen between ART availability in these contexts. The work of specific counsellors, nurses and NGO staff in facilitating the groups' coming together, despite these constraints is more significant.

10 The location for fieldwork sites discussed in this paper.

and arguments within the groups, where personalities clash and also where some are seen to be gaining more advantages than others.

For many people living with HIV, however, the support groups impact only minimally on their lives. Some attend meetings once a month and drop into the centre when they are passing, or on the days when they have appointments, or collect their drugs from the clinic. Others join initially and then do not continue their involvement. For people who do not join or do not attend, there seems to be 'no need' – they see their time better spent attending to usual household duties, or working within their existing social networks. Access to such benefits through group membership has, for many, to be balanced against the real, or perceived, risks of disclosure of HIV status that usually goes along with membership of a public group. In The Gambia many people are HIV-2+, and so have tested positive, often in pregnancy, but have never been, or are very rarely, ill. For many of these people the lived experience of being HIV+ is very different from what might be expected. Disclosure of status to immediate family has generally been a condition of access to ART in The Gambia and this has been a source of contention and controversy. Many people are terrified of disclosure given the high levels of stigma attached to the disease and the potentially devastating consequences for people's social relationships, and this may be a reason for avoiding group membership.

The groups have been strongly criticised by partners in government, clinics and NGOs, for failing to meet expectations. The stress on food provision, so important as a reason for members to attend, had, for instance, by late 2006 become a sign to outsiders of the ways in which the groups were dysfunctional – 'all they do is sit and eat'. For those within NGOs and government who interact with the support societies, their apparent lack of a spirit of voluntarism has been a barrier to good working relationships. Many people see the support group members, and specifically those who hold offices within the structures of the groups, as self interested; looking for free meals, per diems and an easy life and not acting for the common good. Equally, the groups are not seen to act in line with a conception of how HIV-positive people *should* mobilise, based on international understandings and examples of activism. They do not easily conform, in this sense, to the image of active 'therapeutic citizenship' in which HIV positive identity, treatment access claims and an ethical/moral order coalesce, nor can they easily be seen as part of the stable, worldwide formation of such therapeutic citizenship that global commentary is coming increasingly to identify. It is an intriguing sign of the globalisation of such expectations of therapeutic citizenship that institutions working in The Gambia should expect groups to act in this way.

For the active group members – required at meetings to confer legitimacy, for example within the structure of the GF – this lack of financial support creates many problems. They see their salaries as a necessary part of what should be funded, although in the majority of cases these have not been forthcoming. They look at the government, NGO and other agency staff who attend the same workshops and meetings on full salary and receive the same per diems, arriving in air conditioned cars not on public transport, and feel that this illustrates the ways in which the money is not going to those that really need it, and ask; 'why should we work for free?'. For the core staff who attend the centres daily and hold offices

it is difficult – particularly for the men – to explain to their families why when they go out to ‘work’ every day, they do not return with any money. For those who have not disclosed, this inability to contribute to household finances can arouse suspicion among family members, and makes people uneasy.

For members, despite their prime focus on more immediate, localised values of group membership around sheer economic survival and social support, being part of a support society nevertheless means being drawn, to some extent, into such globalised expectations and practices. The political-economic spiral of global funding requires support groups to be included in many structures and committees; this is mandatory, no matter how it is viewed from both sides, in order to signal the legitimacy of these processes to funders within the GF framework. Equally, both internationally and in The Gambia, while the ‘sick role’ associated with HIV might once comprised being wasted and weak, or behaving badly and ‘playing around’, or associated with bad behaviour and ‘playing around’, there is now a second role to which people also feel pressure to conform after diagnosis: to work tirelessly as an advocate and project manager, or at least to take part in meetings and income generating activities, such as making soap and tie-dye materials. Over time, and through interacting with partners and attending meetings, group members – particularly the leaders and those with positions – have learnt what the international community and the GF expects of a committee, its leaders and members. They have learnt the expected procedural expertise, and to enact this effectively. The values involved are sometimes quite alien to prevailing social norms, for instance in their expectations about women representatives, gender and decision-making. They involve talk that people often find alienating, irrelevant or frustrating: for example ‘Yes, I went there [to a meeting] but it was just “stigma and discrimination” “stigma and discrimination” ... talking about nothing’. Yet people are well aware that speaking the language of funders and intermediary NGOs is the key to having productive engagements with them. This is also, therefore, the key to the material benefits that for many were a principle reason for joining the groups. For many people, the per diems, lunches and so on associated with group meetings have become their major source of income. Indeed there is one example of a support group member who was discovered, after some time, to be HIV negative. He had faked it, in order to access HIV-related income. However, social cohesion being as it is he was not expelled from the group and is now more secure than many members, working within the group and drawing a salary.

Another issue which arises around the management of the groups is that of ‘ownership’ by intermediary organisations. Certain NGOs and organisations, as sub-recipients of the GF grant or otherwise, fund group activities and core functions: rent and utility bills for example. From their inception various people have taken prominent roles in setting up and supporting the different groups. However, there are only a few groups, and there is sometimes competition between organisations and staff to work with them, and resentment when they see others as interfering with ‘their’ support group. Rather than facilitating group members’ ability to negotiate and press for their own priorities, this competitive situation generally became a minefield in which group managers were seen as ‘dishonest’ in not disclosing to one organisation what another was funding, and taking advantage of overlapping programmes – such as two organisations

providing the same training. For instance, one group member showed Cassidy all the certificates he had for management training. Spreading them out on the floor he said, 'They're all the same. But what's the point. I can never use what they tell me'. The main function and benefit of these repeated trainings, to this man, was the food provided on the day and the per diem, as well as to fulfil programme priorities – despite these being removed from the daily realities of those the programmes aim to serve.

Within and between the groups there was also competition for scarce resources; when meetings or workshops come up the decisions as to who represents the groups, and how many delegates, from which support groups, has often caused tensions. Through 2006 the national network of people living with HIV was set up, and this involved many power plays between different members, given that representation equals a more secure livelihood. Within the groups those seen to be more educated, invariably the men, could take part more easily. Tensions over the use of English or local languages, and the ability to read and take notes, meant that the majority of members – illiterate women – were seen not to be equipped to represent themselves or the groups. During the meeting to discuss the constitution of the new national network it was decided that non-Gambians ('foreigners' from neighbouring countries) could not hold positions, despite the fact that these foreigners were in some cases highly literate and active members. This was seen by some to be a deliberate act by prominent Gambian members to control who could be eligible for the associated benefits and protect their own interests. Members of groups up-country also felt that the original groups around the coastal peri-urban area held a monopoly on these invitations. And within these groups, those members who were more 'active' – attending regularly – and more 'educated' tended to hold a monopoly on workshop attendance and therefore this income stream. Both some group members and others from partner organisations with ideals of participation and gender equity went some way to try to spread the benefits; however the practical realities of working with people who could not conform to the norms and practices of such meetings easily, without language difficulties, would, more often than not, overcome these concerns.

Alongside these crucial material dimensions to HIV support group membership, there are also epistemic ones. Being part of a group, to some extent, involved subscribing to dominant globalised framings of the nature of disease. Thus the GF and associated institutions constructed HIV in biomedical terms and as amenable to drug treatment through ARVs, rolled out in clinic settings. The strong links between the individual clinics and the support groups, and the referral of people to groups in the context of treatment interactions, emphasised such views of disease and treatment. This is in a broader Gambian context in which Gambian understandings of illness and therapy are pluralistic, appealing to different disease aetiologies that range from viruses ('disease seeds') to witchcraft, sorcery and Allah, and therapies ranging from biomedical drugs and vaccines, to herbs, to amulets. For some illnesses, these are complementary. Other diseases are seen as exclusively amenable to one kind of therapy or the other. Yet it appears that being part of an ART regime and associated support group membership has gone along with a reinforcement of biomedical perspectives as the exclusive frame in which HIV could legitimately be discussed and treatment sought. In interviews through 2006, group members would sometimes speak about traditional medicine.

However, all were very careful to stress that they no longer sought this kind of treatment and that they were 'with the clinic now'. Counselling at all the clinics involved a strong message that mixing local treatments with ART was unacceptable. Although many people said that *other people* did this, no one wanted to discuss their own transgressions. The shared experience of being in a support group in turn meant that the message of ART as the only and best way to deal with HIV was reinforced for many by not only their own but their friends' experiences. Particularly those who are HIV-2+, who have never been sick, witnessing people become progressively sicker and then recover their health provided experiential evidence not only of the power of these drugs, and also to some extent the existence of HIV.

Thus the patients' support groups in The Gambia have, for their members, been primarily experienced as routes to seek vital economic and social support in local conditions of extreme poverty and deprivation. For some, they have also provided an important community. While medical and NGO discourses around individualised rights and democracy are sometimes taken on board and used, they are also rejected in favour of more comfortable family and kinship ties. These primarily local meanings have been cast as problematic by actors in the globalised policy processes around funding and treatment, who expect people living with HIV to conform to particular views of global therapeutic citizenship. Yet at the same time, group members have (as a necessary route to access material benefits) become caught up in such dominant spirals of globalised citizenship and power-knowledge: enactors of their procedures, and bearers and performers of their notions of disease and therapy.

5 Conclusions

This paper has traced local-global forms of citizen engagement with the globalism of the new international public health, with its biomedical framings and authority structures such as the Global Fund and its implementing agencies. This case illustrates a recurring contemporary pattern whereby global health programmes encounter reinterpretation at local and national levels in ways that can disrupt their original aims. It also highlights the ways in which people, the beneficiaries of these programmes, as well as the in-country staff of implementing organisations, struggle to make sense of the values they impose. There are major challenges for global health programmes, NGOs and social movements in framing their interventions given such epistemological and political realities.

We have argued that at one level, the GF treatment programme constructs notions and possibilities for citizenship: defined in terms of an HIV-positive identity, and individualised rights-claims with respect to biomedical treatments. This is a notion of citizenship constructed in accordance with a particular, dominant, globalised narrative about AIDS response (Edstrom 2008). Yet in 'seeing like a citizen', examining the experiences, perspectives and practices of people living with HIV and their support groups, we have seen that people's priorities lie around the immediate social and livelihood benefits that come with associating with local-global regimes. They are often prepared to assimilate the procedures,

practices and discourses necessary to access these benefits. For people so extremely poor and vulnerable, in these power-effects such global initiatives sweep people up into a vortex of discourse and procedure that may look like local-global citizen engagement but is perhaps better cast as subjection to governmentality.

This is not to suggest a lack of agency or reflection amongst Gambian citizens. Some people living with HIV have certainly come to reflect and speak actively about treatment rights and claims. Arguably the support groups create a space for active engagement and rights-claiming in the GF context, limited as this has sometimes been by the GF's structures of mediation and implementation as they have played out in The Gambia. It is also arguable that NGO work on gender empowerment, specifically with the support groups, provides the thin end of the wedge to make gains and changes on these issues in this very male-dominated society.

Furthermore as our exploration of people's engagement with the support societies begins to reveal, there are many other meanings and expressions of rights and citizenship in The Gambian context that may be more significant to people in their daily lives. These include membership of family, neighbourhood or community, and the informal economic and social rights that come with this, as well as notions of what it is to be Gambian or a foreigner. These, and other, meanings of citizenship find some expression and reinforcement in the ways that people, in practice, make use of support groups and live with HIV. However, such expressions of citizenship are marginalised – and sometimes the subject of outright disapproval – in relation to notions of what individualised therapeutic citizens ought to be like according to dominant global AIDS narratives. Recognising and enabling alternative forms of AIDS-related citizenship, in the Gambian context as elsewhere, is thus a compelling task for future research and advocacy (see MacGregor and Edstrom 2008).

Understanding contemporary citizen engagements in a globalised world will thus have to contend with the grounded economic, social and political realities which shape how people frame and prioritise their rights claims. It also needs to contend with the realities of power dynamics which limit some expressions and practices of citizen agency, while promoting others. In settings where all of this is in play, local-global citizen engagement – whether in relation to health, or other issues – may come to look different indeed from the forms which capture the imaginations of analysts and activists alike.

References

- Alliance (2007) *L'Observatoire: La Transformation de la Réponse au VIH/SIDA au Sénégal Grâce à l'engagement de la Société Civile*, Policy Briefing, International HIV/AIDS Alliance. www.aidsalliance.org/custom_asp/publications/view.asp?publication_id=265
- Bernstein, M. and Sessions, M. (2007) *Trickle or a Flood: Commitments and Disbursement from the Global Fund, PEPFAR, and the World Bank's Multi-Country AIDS Program (MAP)*, Washington DC: Center for Global Development
- Birdsall, K. and Kelly, K. (2007) *Pioneers, Partners, Providers: Dynamics of Civil Society and AIDS Funding in Southern Africa*, Johannesburg: Centre for AIDS Development, Research and Evaluation
- Brugha, R. (2005) *Global Fund Tracking Study: A Cross-country Comparative Analysis Final Draft*, 2 August www.ghin.lshtm.ac.uk/downloads/publications/Brugha_et_al_cross_country_analysis_2005.pdf (accessed 23 July 2007)
- Dry, Sarah (2008) *Epidemics for All? Governing Health in a Global Age*, STEPS Working Paper 9, Brighton: STEPS Centre
- Edstrom, J. (2008) 'Constructing AIDS: Contesting Perspectives on an Evolving Epidemic', paper presented at workshop on Epidemics, STEPS Centre, Brighton, 8–9 December 2008
- Foster, G. (2005) *Bottlenecks and Drip-feeds: Channelling Resources to Communities Responding to Orphans and Vulnerable Children in Southern Africa*, London: Save The Children
- Global Fund (2002) *The Framework Document for the Global Fund to Fight AIDS, Tuberculosis and Malaria*, www.theglobalfund.org/en/files/publicdoc/Framework_uk.pdf (accessed 23 July 2007)
- Haas, P. (1992) 'Introduction: Epistemic Communities and International Policy Coordination', *International Organisation* 46: 1–36
- Knorr Cetina, K. (1999) *Epistemic Cultures: How the Sciences Make Knowledge*, Cambridge and London: Harvard University Press
- MacGregor, H. and Edstrom, J. (2008) 'Health-related Identities and Citizen Claims Beyond the "Therapeutic": Interactions of Public Health Responses with Diverse New Claims for Representation and Recognition', paper presented at the CRESC Conference on Culture and Citizenship, Oxford, 5–6 September 2008
- Nguyen, V.-K. (2005) 'Antiretroviral Globalism, Biopolitics, and Therapeutic Citizenship', in A. Ong, and S. Collier (eds), *Global Assemblages: Technology, Politics and Ethics as Anthropological Problems*, London: Blackwell
- Robins, S. (2006) 'From "Rights" to "Ritual": AIDS Activism in South Africa', *American Anthropologist* 108.2: 312–23
- (2005) *From 'Medical Miracles' to Normal(ised) Medicine: AIDS Treatment*,

Activism and Citizenship in UK and South Africa, IDS Working Paper 252,
Brighton: IDS

White, L. (2005) 'The Needle and the State: Immunization and Inoculation in Africa. Or, the Practice of Un-national Sovereignty', paper presented at the conference on 'Locating the Field: The Ethnography of Biomedical Research in Africa', Kilifi, Kenya, 4–9 December 2005