

THE POLITICS OF GLOBAL ADVOCACY AND ACTIVISM AROUND HIV/AIDS

**Report on Workshop held at the International Centre for Participation Studies (ICPS),
Department of Peace Studies, University of Bradford, 9 July 2009, by Nadine Beckmann**



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Workshop Aims

What has happened to HIV/AIDS activism and advocacy? Almost three decades into the pandemic, HIV/AIDS continues to cause great suffering, stigmatisation, and loss of life. While the importance of engaging HIV positive people in the response to HIV/AIDS at all levels has been formalised in the adoption of the GIPA principle of 1994, their meaningful involvement is by no means a given. Since the early 1980s people living with HIV/AIDS have been mobilising to make their voices heard. This workshop aimed to take a step back and critically rethink this mobilisation and the challenges it has faced, asking in the last instance if activism and confrontational mobilisation is the best response and mapping the spectrum of responses. It was an informal encounter between academics and activists from global and national networks of organisations working with HIV/AIDS.

Participants, Organisation and Key Questions

The workshop brought together people from academia, activism, and non-governmental organisations (for full list see Appendix A). Some participants focused on AIDS activism directly or were involved in HIV/AIDS service delivery; others were part of or researched social movements, civil society, or gender and development more broadly. It provided the space for an open exploration of concepts that are often taken for granted: the democratic model used to ensure fair representation and authenticity, the increasingly global nature of advocacy and activism, the ultimate value of social movements and confrontational politics, of the metaphor of war and PLHA's 'struggle', as means to reach their goals. The workshop fed back from the ESRC funded research project (part of the Programme on Non-Governmental Public Action) on the politicisation of AIDS activism and HIV positive people's collective action around HIV/AIDS in Tanzania carried out in 2007/8. It used the Tanzanian and the South African examples as case studies to trigger questions and debate. However, it was deliberately designed as an informal forum to open up space for the discussion of more general questions around representation, movement building, and strategies for advocacy (see agenda in Appendix B).

In her introduction, Professor Jenny Pearce, principal investigator of the ESRC-funded research project 'The politicisation of AIDS activism in Tanzania', located our work in the field of participation studies which analyses diverse forms in which people take part in the social and political spheres, looking at collective action, social movements, and invited spaces of participation which are being created from above, to investigate how social and political change takes place. Our research project is part of the ESRC's Non-Governmental Public Action Programme, which offers a broader framework than 'civil society' as a means of exploring social action outside the state, and broadens it so that it embraces a wider range of different types of action and activism in the public sphere aimed at impacting on policy

¹ Contact: Nadine Beckmann (n.beckmann@bradford.ac.uk), Janet Bujra (j.m.bujra@bradford.ac.uk), Jenny Pearce (j.v.pearce@bradford.ac.uk)

and building new visions for societies' future. We found a body of literature that flags the powerful moments of AIDS activism, where strong international alliances were formed and significant victories achieved. But the research in Tanzania showed that there, such activism is largely lacking, or very weak. This tension framed the debates of the day: in what contexts, we were asking, does which kind of activism emerge around HIV/AIDS? How does what happens at the local level relate to the large international campaigns that are going on? Whose voices are coming into these debates, and what are the claims, demands, and identities that are formed through AIDS activism?

The day was loosely structured in three sessions, addressing questions around representation, authenticity and agenda building, around social movements and the value of attempts to establish a global civil society versus the building of national movements, and around strategies for mobilisation, discussing the use of advocacy and 'dialogue' (or insiderism?) versus more confrontational politics.

Conference Discussion: A Summary

Julian Hows, programme officer of the Global Network of People of Living with HIV/AIDS (GNP+), and Adela Mugabe, regional coordinator of Manchester and founding member of PozFem UK (the UK's network of HIV positive women) introduced their organisations' main approaches, key achievements, and challenges. One focus of the day was on the tension between local and global spheres: while 'the local is increasingly constructed by global forces' (Richey 2002), global



Julian Hows presenting GNP+'s approach

discourses are also constantly being reworked at the local level (Beckmann and Bujra 2009). One issue that keeps coming up as a central problem is the question of representation, of who has the authority to speak on behalf of others: the PLHA networks face the constant challenge to improve their responsiveness to their constituents and to professionalise their approach to using evidence to inform policies and programmes.

Julian Hows from GNP+, who is a long-term activist coming from the gay liberation movement of the 1970s, and involved in AIDS activism since he was diagnosed HIV positive in 1983, pointed to the fundamental difference between social movements, which are sets of beliefs and principles that individuals sign on to and membership-based organisations (such as GNP+) that can get in the way of such activism. On the other hand, one workshop participant pointed out, organisation is needed to form a movement: an agreement of opinion must be translated into action in order to create change, and this must be organised and coordinated. Julian emphasised that part of the reason why we have managed to create some social movements and activism which is outside the norm of the mainstream development paradigm, derives from the exceptionalism of HIV/AIDS. He also flagged up the problematic nature of the 'democratic pyramid' – where global networks work with national networks,

trusting that they in turn work with the grassroots at the local level– , on which organisations like GNP+ are predicated and the ensuing challenges to authenticity and representation.

GNP+ is a network of six regional networks. Due to pressure from the institutions they need to engage with (e.g. UNAIDS, national governments, international funding mechanisms) it was forced into adopting a structure that mirrors government structures or what we might call, ‘artificial democracy’, following the model of the ‘democratic pyramid’, from the local, to the national, to the regional. Applied to a social movement the weight of this form of democracy, of bureaucracy and funding demands, means people spend their time as politicians, rather than representatives, trying to get to the top of the pyramid rather than articulating concerns. It also means that the networks, like governments, involve themselves in regime change, put in place puppet representatives, and produce despots. This poses a continual challenge to GNP+’s regional networks and periodically compromises their claims to authenticity. GNP+ realises that this is a constant challenge, and tries to counter this imperfect structure by both looking reactively at what is happening to PLHA in the world and



Small group discussion with Adela Mugabo

proactively at what is coming down the pipeline: it uses a stranded approach that has consultations around various issues happening at the global and at the local level to ensure authenticity. This is achieved by constantly reflecting on a number of questions: have we talked to the people? is the demographic base of those we talked to broad enough? and is it evidence driven? To address these questions, GNP+ has developed research tools designed to create an evidence base for their global advocacy agenda, capturing

wider issues, not just anecdotes (as was the practice with testimonies presented at conferences and meetings). The PLHA conference that they organise as a side show to the International AIDS Conference, for example, is the culmination of 18 months of regional, local and email-based consultations with people with the capacity to get involved around certain issues. These consultations take place in partnership with ICW, GNP+’s regional networks, and other partners and culminates in the creation of an agenda for action that microphones the concerns of HIV positive people around the world. This will always be imperfect and mitigated by the fact that a large majority people do not have access to these consultations, and representation is certainly skewed towards middle-class, urban participants, with the majority of PLHA, rural and poor urban sub-Saharan Africans finding it more difficult to become involved. The lack of emphasis of global AIDS activism on broader issues of impoverishment and social injustice may be a direct result of this. But Julian pointed out that we are sometimes patronising in our assessment of the capacity and willingness of people to be involved: people can and do overcome language barriers, travel restrictions, and lack of access to communication technologies but still find ways to make their voices heard.

Adela Mugabo came to the UK in 2002 and was diagnosed HIV positive in 2003. She then became engaged in a number of AIDS activist organisations and provided a slightly different

view: that of people living with HIV/AIDS in the global South, in East Africa specifically, and insights into the particular challenges women living with HIV/AIDS face. She pointed to the persistent silence about HIV/AIDS in her home country Uganda, but equally among certain groups in the developed world, both inhibiting access to information, support and participation in activism. White women or drug users, for example, often struggle to access support groups and do not feel their concerns are represented when the majority of group members in their areas are gay men or Africans. PozFem UK counters this problem through reaching out to those who are hard to reach, through offering an e-forum for members, and through providing a safe space for women to call and voice their needs and concerns. Their approach is one of ‘empowering and enabling’, mainly through the provision of quick information on new developments and of education on a variety of issues, ranging from HIV/AIDS, to violence against women, questions of treatment and health services, self-esteem, rights, workplace policies etc. Being recognised by the Department of Health they also influence the policy level through consultation processes.

An ongoing problem in AIDS activism is the inclusion of diverse subjectivities and identities in the face of stigmatisation not only from outside, but also within the global community of PLHA: a lot of early AIDS activism came out of the gay movement, initially with little involvement of drug users, sex workers, or straight women. But how does one identify which are the relevant categories to include and represent? For example, gender and sexuality, route of HIV transmission, ethnicity, country of origin and of



Small group discussion

residence feature strongly in the attempts to show the diversity of PLHA, while class has not figured very much – quite possibly a result of problems in the flow of communication within networks of AIDS activism from the Southern poor to the global level. The process of working through those dynamics is perhaps the most interesting, and the most challenging one to address in AIDS activism. Stigmatisation and discrimination within the broader HIV community further complicates the potential for creating an inclusive environment: racism, homophobia, and sexism have to be overcome if solidarity is to be built. Thus, for the people involved, engaging in AIDS activism is an ongoing learning process in which individuals have to work on and rise above their own prejudices. One of the reasons why Tanzanian AIDS activism has not moved from the discussion of HIV/AIDS issues to claims for broader issues, e.g. social justice, may be that a movement has to put forward commonalities on the basis of which people can act collectively. To achieve this it needs to address the things that hold back these commonalities and create differences. Through this, a progressive politics can emerge out of movements, which gives them the potentiality which is perhaps not there for separate organisations that are funded by donors.

One challenge in the building of movements is finding a balance between making linkages with other movements and addressing broader issues while at the same time retaining the

AIDS exceptionalism that contributes to AIDS activists' political mobilisation. Pragmatism sometimes characterises the definition of issues in order to keep one's goals achievable: GNP+ for example, focuses on travel restrictions for HIV positive people as an HIV/AIDS issue, rather than as a broader issue of xenophobia, migration and equity. Moreover, the forging of alliances has often been problematic, hampered both by stigmatisation – due to its association with death and immorality – and by differences in preferred strategies. This is the case, for example, when potential partner organisations have settled into a cosy relationship with the government which they may fear to be endangered by the more confrontational stance of AIDS activists.

Another tension that pervades the work around HIV/AIDS is that between service provision and mobilisation. Many HIV positive people look for groups in the search for support – secrecy and the fear of stigma inhibits their willingness to participate in political mobilisation. There is a difference between secrecy and confidentiality, however, and the fear of stigmatisation is precisely the reason why activism is needed: HIV positive activists act as representatives because the person who should be speaking is too frightened to do so. Therefore, networks like GNP+ and ICW+ capture the voices of PLHA around the world and



Janet Bujra presenting findings from Tanzania

voice their concerns. Service delivery, it was pointed out, saps the strength of a movement, since it takes up too much energy and resources and thus diverts these away from the focus on activism. This is why the networks explicitly and deliberately do not engage in service delivery, unless it serves to produce evidence and legitimacy. For example, providing services means being in touch with the people they want to represent.

The global networks' main role lies in creating a global environment that is enabling and empowering, where empowerment is meant as giving people the capacity to act: trying to change the global policy architecture so that local groups can do their work more effectively. However, local groups often look at what is effectively a global secretariat as a parent, expecting patronage, while the global networks would prefer to be seen as more horizontal.

Discussing the underlying reasons of South African AIDS activism's much celebrated success in building a strong social movement around the issue of access to antiretroviral treatment, and of the failure to achieve similar successes in Tanzania – and indeed the majority of countries in sub-Saharan Africa – the importance of the particular political environment, the political opportunity structure as Sidney Tarrow put it, was emphasised. South Africa's Treatment Access Campaign (TAC) unfolded at a unique political moment in the history of the country, after the end of the Apartheid state. It was achieved through the persistent political mobilisation of people who had become skilled activists, at a time which saw the flourishing of ideas around citizenship and civil society, and the return of the Diaspora community with their own experiences of citizen rights and a willingness to engage

with the state about them. At the same time, Mbeki's strong denialist stance radicalised the HIV community, providing a prime enemy target, and TAC was able to create alliances with intellectuals and professionals from a large educated middle class, strong trade unions, a vibrant gay activism movement, and to tap into a global network of supporters in situations where they were not able to create sufficient pressure from below. Brazil, with its long history of social movements against military dictatorship in the 1970s and 1980s, also generated a vibrant HIV activist community. In that case, they were able to have a strong influence on the State and to ensure that it responded to the needs of that community.

Several workshop participants emphasised the importance of 'thinking globally and acting locally': local activism expands possibilities at the global level and the global level, in turn, feeds back to the local level, can be tapped into when the national structures do not allow for effective mobilisation, and can redefine the discourse to make changes at the local level and national level possible. The building of national movements and global civil society thus needs to be interrelated; one cannot exist without the other.

But what happens if a movement does not emerge? Does it actually matter? As a general rule, it was pointed out, if people are happy with the status quo, there is no need for mobilisation. But when a group of people is interested in changing the status quo and when it is marginalised, a movement is needed. Conflict is built into politics, and without some measure of mobilisation and politicisation



Small group discussion

exploitative structures can take hold more easily. One thing that the Tanzanian research showed is that in the absence of a movement and fostered by the donor community, you get a large number of fragmented groups arising at the local level. This actually may impede collective action, the process of putting ideas into the public sphere and creating a pluralistic debate. At the same time, the attempt to instil such collective action through external influence, such as through the funding of groups and activities, is highly problematic: people act upon issues they find important and believe in. Trying to inspire this belief in the importance of a certain issue is perhaps one of the biggest challenges activism faces. Even where there is fragmentation, however, this does not necessarily mean that the issues are not being discussed and addressed at all, especially when the national government's approach to HIV/AIDS is generally benign. The question is whether this can happen on its own, or whether it needs confrontation and pressure to adopt such a stance.

So, the final set of questions the workshop addressed revolved around the strategies for mobilisation: do we actually need confrontation? Is confrontation always desirable? In Tanzania, for example, people go a long way to cover up differences and sustain consensus and harmony, even in the face of quite visible abuses of power, because here the promise to maintain non-confrontational politics can be a considerable resource. In a context of donor

dependency, the motto is: 'whatever happens, don't split the party', so that donors will continue to have a single interlocutor and continue business as usual. Those workshop participants who study social movements, however, highlighted the importance of antagonism as a source of civil society power. At the root of social movements' power bases, they argued, are autonomy and confrontation with authorities, be they national governments or indeed multilateral agencies and transnational corporations. But, for pragmatic reasons, some engagement with the state might be necessary, and more efficient in reaching one's goals, even though this always bears the danger of cooption. Ultimately, what is needed is flexibility between alternatives and a deliberative way of decision making, always balancing ideals versus the reality on the ground, as structural factors influence decisions taken. But is mobilisation without confrontation possible? Julian reminded us of Monica Scharma's (UNDP) pledge to take the language of war from HIV, and instead view social mobilisation as assertion, as laying out our own view, as a silent revolution, and thus as mobilisation without confrontation.

Concluding the day's vibrant and interesting debates, Jenny made the case for the importance of movements that are politicising and transformative of one's own capacity to make change while recognising other people's claims and needs: one thing that came out in our discussions is that it is precisely in the movement where the idea of reaching consensus by working out differences takes place. Because people are beginning to organise around HIV, they are bringing to the surface something that is virtually unmentionable. This process of bringing issues that have to be discussed forward is what eventually brings society forward.

APPENDIX A: LIST OF PARTICIPANTS

'The politics of global advocacy and activism around HIV/AIDS'

9 July 2009, Bradford

Name	Organisation	Role	E-mail
Alexandra Abello-Colak	ICPS, Department of Peace Studies, University of Bradford	PhD student	A.Abellocolak@Bradford.ac.uk
Abimbola Alabede	University of Bradford- Red Ribbon Society	Student	zeeb007@hotmail.com
Nadine Beckmann	ICPS, Department of Peace Studies, University of Bradford	Research Fellow	N.Beckmann@bradford.ac.uk
Jelke Boesten	Politics and International Studies, University of Leeds	Lecturer in Social Development and Human Security	J.Boesten@leeds.ac.uk
Josh Brem-Wilson	ICPS, Department of Peace Studies, University of Bradford	PhD student	jwbremwi@bradford.ac.uk
Janet Bujra	ICPS, Department of Peace Studies, University of Bradford	Honorary Reader in Peace Studies and consultant on the ESRC project	j.m.bujra@Bradford.ac.uk
Ben Gross	Department of Peace Studies, Bradford	MA student	gilgamesh36@hotmail.com
Julian Hows	Global Network of People living with HIV	Programme Officer	jhows@gnpplus.net
Moritz Hunsmann	EHESS and <i>Albert-Ludwigs-Universität</i> Freiburg	PhD student	Moritz.Hunsmann@ehess.fr
Amalberga Kasangala	University of Bradford	Student	aakasang@bradford.ac.uk
Laurie Lynn Kelly	University of Hull	PhD student	Laurie.Kelly@hull.ac.uk
Fiona Macaulay	Department of Peace Studies, University of Bradford	Senior Lecturer in Development Studies	f.macaulay@bradford.ac.uk
Adela Mugabo	PozFem UK	Regional coordinator for Manchester	dellamah@yahoo.co.uk
Anna Mdee	Department for Development and Economic Studies (BCID), University of Bradford	Senior Lecturer, Director of the Postgraduate Programme	A.L.Mdee@Bradford.ac.uk
Wellington Moyo	The Our Project	CDW	
Lorraine Mponela	University of Leeds	Masters in Public Health student	lmmponela@yahoo.com
Judie Mwarabu	Fisherfolks Trust, Tanzania	Trustee	judieminardsmwarabu@gmail.com
David Ndiwanyu	The NILE African Development Organisation	CEO	nileafrika@africanachievers.com

William Obubo	University of Bradford Red Ribbon Society	Student	billy7bones@hotmail.com
Ochiabuto Ogechi Perpetua	Leeds Institute of Health Sciences, University of Leeds	Student	ogepo@yahoo.com
Jenny Pearce	ICPS, Department of Peace Studies, University of Bradford	Professor of Latin American Politics, Director of International Centre for Participation Studies, team director for the ESRC project	J.V.Pearce@Bradford.ac.uk
Relebohile Pii	University of Bradford Red Ribbon Society	Student	pii.thato@gmail.com
Larenda Twigg	Department of Peace Studies, University of Bradford	Student	l.n.twigg@bradford.ac.uk
Polly Wilding	Centre of Development Studies, University of Leeds	Lecturer in Gender and International Development	P.Wilding@leeds.ac.uk

APPENDIX B: AGENDA

'The politics of global advocacy and activism around HIV/AIDS'

International Centre for Participation Studies (ICPS), Department of Peace Studies
9 July 2009, University of Bradford, Conflict Resolution Room (Pemberton Building)

What has happened to HIV/AIDS activism and advocacy? Almost three decades into the pandemic HIV/AIDS continues to cause great suffering, stigmatisation, and loss of life. This workshop feeds back from a research project on the politicisation of AIDS activism and HIV positive people's collective action around HIV/AIDS in Tanzania carried out in 2007/8. The project explored why in contrast to South Africa AIDS activism in Tanzania has only emerged in a limited form. Yet, there are significant global campaigns around HIV/AIDS – but what are the connections between these global campaigns and the people living with HIV/AIDS on the ground? This is an informal workshop in which people will present their ideas, experiences and research findings, rather than formal papers. It is intended to open up space for discussion of the implications of our findings for the Tanzanian situation, global AIDS activism, and for global advocacy.

Programme:

8 July, 19.30 Dinner with conference delegates

9 July, 8.30 **Registration**
Tea and coffee will be available

9- 9.15 **Introduction and welcome** by Professor Jenny Pearce

9.15– 11.00 **Session 1: Whose voice, whose agenda? Establishing the parameters for AIDS activism**

Chair: Nadine Beckmann

Brief introduction by Julian Hows (Global Network of People Living with HIV/AIDS) and Adela Mugabo (PozFem UK) on the bases of their approaches, the key achievements and challenges (10 minutes each)

Questions to address: How are messages and agendas created? How to ensure that the grassroots have a voice in the processes of identifying direction and strategies? What are the tensions between the different levels of HIV/AIDS representation (i.e. grassroots, national, global)? What is the value of approaches based on the human rights paradigm and biomedical evidence when parts of the PLHA community particularly in the global South may argue within different frameworks?

11.00 – 11.30 Tea break

11.30 – 13.00 **Session 2: Building movements**

Chair: Jenny Pearce

Introduction on findings from Tanzania by Janet Bujra (10 minutes)

The South African treatment action campaign has been the only strong movement around HIV/AIDS. How can we make sense of its success, and of the failure or weakness of movements in other countries? What are the goals of collective action around HIV/AIDS – establishing a new form of global civil society, or the building of local movements, facilitated by the support of global networks like GNP+ and ICW+? What are the values and trade-offs of a holistic approach that asks for large-scale social transformations as opposed to an issue-based approach that mobilises around certain predefined topics (such as stigma, workplace policies, treatment, prevention etc.), and is either possible without the other?

13.00 – 14.00 Lunch

14.00 – 16.00 **Session 3: Alternative strategies: advocacy and ‘dialogue’ (or insiderism?) versus confrontational politics**

Chair: Jelke Boesten

Introduction on findings from Tanzania by Nadine Beckmann (10 minutes)

What alternatives are there for mobilisation and collective action around HIV/AIDS? How do we define advocacy and activism, and on what assumptions are these approaches based? What roles do insiderism, dialogue, and confrontational politics play respectively? What are the differences between the work of NGOs and other forms of collective action?

**International Centre for Participation Studies
Department of Peace Studies
University of Bradford
BD7 1DP**