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The Politics of Global AIDS

Institutionalization of Solidarity,
Exclusion of Context



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For my mother Beyhan and Damien

Preface

Field Notes from Global AIDS

On this particular day, we were visiting a prison outside of Bujumbura (Burundi). I had heard that a number of people had organized themselves as an HIV-positive support group to help each other in the prison, so I wanted to talk to them for my research. The meeting had been arranged through a local human rights lawyer who worked for a non-governmental organization (NGO) and was aware of the group.

We arrived at the prison. It was outside Bujumbura, but not too far away in the middle of the countryside. My first impression was that there were too many people and it was really crowded. We were taken through the corridors to see the prison administrator first, women and men were separated, but both sides of the prison were very noisy, and many people were behind bars; inside people were cooking, I could smell the fire and food, it was very busy, and the corridors were hard to pass through. The person who was facilitating this meeting – George (a pseudonym) – was telling us that the prison had at the time over three times the prisoners that it should have contained. We were taken into an area a bit like a shed with an open front looking to the front yard of the prison. Three prisoners were allowed to come and talk to us there: One of them was the young man who had initiated the support group for HIV-positive prisoners. He talked about how they started the group to help themselves because there were no other resources to support them in the prison. They were cooking food and selling it to make money to support their HIV-related needs. He said that they did not need to go out and look for people to join them because word of mouth brought people to their group. He added that ‘many people don’t know they have HIV and get really sick while in the prison, and they are diagnosed, but there are no real resources to support them after the diagnosis, and some don’t get diagnosed at all, we just know the signs’. The main problem he said, pointing the oldest man in the group, was that, for instance, ‘he is really sick; he needs to get proper treatment outside, but he cannot get out from the prison since for months he is waiting to see the judge’, to be told whether there will be a case against him or not. ‘There are so many people waiting to be charged for months; there are many

people like this; some even die in the prison waiting to see the judge'. Given that 'many people don't come from this area, they don't have relatives to come and support them with food', so people were reliant on the very little that can get within the prison. That's 'why we started this group. But it is not enough. We were told that if you are sick like us, they will release us, but still nothing has happened'.

George also explained that sometimes the group got help from international NGOs but that this was not enough. I asked whether people acquired HIV in the prison. I had to ask this question very carefully. Given the gender segregation, it was a sensitive issue touching on same sex-related taboos. He said that they thought some women might catch HIV as there were ways of having sex with women even if they were living in separate parts of the prison. Then I asked how about the men. He was more cautious but said that 'younger men, who are not from this area, work for older and richer men. They cook for them, clean the place they sleep; they become dependent' on the relationship to survive, and 'sometimes they are very close' because otherwise they would have had nothing to survive. He stopped at that. It was a difficult set of interviews, and it was even harder to think what one could do to influence change in these circumstances and who I should talk to... (December 2008).

It was 2010 and I was in Vienna (Austria) for a meeting of the *Thinking Politically* group held at the XVIII International AIDS Conference. The meeting seemed to be a joint initiative between the International AIDS Society (IAS) and UNAIDS. Dennis Altman and Kent Buse were the planners and, I assumed, the main motivators behind the initiative. They were really enthusiastic and had gathered together a group of political scientists from across the globe. We had a good meeting, discussing different ways of motivating political science research on HIV and how to bring existing research in this area to engage with the epidemic. Our concern though was also with the broader context of the IAS and how best to bring relevant research to the attention of policymakers. It was a discussion about political science but also touched on the strategy of how to engage with various groups from this particular perspective. Dennis and Ken did a good job in arranging a 'networking' lunch, which included some important and influential policy actors. One of them, a person who was at the top of the policy chain, in a discussion turned around and said that the main problem with AIDS today was its over-medicalization. I could not believe my ears; I was rather perplexed thinking that medicalization did not happen naturally. I was wondering what was being done to address this issue given that the person was in position of responsibility. It was rather an odd way to start the conference process. I was buzzing with ideas from the meeting as we had had a good discussion, but I also did not know what to think about this statement concerning medicalization in relation to the conference programme... (July 2010).

After a few weeks in Gulu (Uganda), I managed to go to the hospital to look at their HIV clinic. The hospital there was very important as it not only provided health-related services to a wide area but also, as I was told by the priest who had taken me to the hospital, because a lot of people had sought refuge in the hospital during the Lord's Resistance Army (LRA) troubles. There were a lot of people waiting outside. He mentioned that some of these people came from South Sudan every

morning as this was the biggest facility available. The inside was also busy, with many people who must have been relatives sleeping outside the wards. The HIV unit, around a courtyard garden, was quieter; it must have been the time of the day. I met the doctor responsible for the unit. He was very welcoming and talked about ARV provision and other issues they were facing. It seemed that they were able to engage their patients in a structured way to provide ARV, and he said that the hospital had good relationships with its patients. Then he began to talk about other problems: '[But] we sometimes received letters from people from villages – not near here in the bush – asking us to give them ARVs. They say that they were on treatment provided by an NGO, but for a few months now they have not had anyone coming from the NGO to give them treatment, so they don't have medicine and that they are worried'. The problem was that 'we have limited supplies related to the number of patients we have, [so] I cannot suddenly provide medicine to unexpected others'. This would have put "my patients"' treatment into danger'.

Another problem he highlighted was that since the peace, people were now travelling more so they could get access to treatment, and they often travel elsewhere in the country: 'We don't know what happens to these people, whether they then get access to treatment elsewhere or they stop'. He went on, 'We also have problems with men'; women get their treatment for a month, and then they came back earlier to get more. He said that 'men are using their wives' pills knowing that if she has AIDS, I must too, but they do not want to come to the hospital. This is also making the management of treatment difficult'. It struck me that these were all important challenges in this remote part of Uganda. Also I was not sure how things would work out in the future as the closure of The AIDS Support Organization (TASO) treatment centres was being discussed. He did not say a lot about the Sudanese patients, but I wondered whether they were also receiving treatment through this hospital, which was resourced through the Ugandan (Global Fund) mechanism... (August 2012).

Sitting through the panel presentations (at the 2012 AIDS Conference, Washington D.C., USA) was tedious. Speakers made massive generalizations from rather small sample groups to talk about the usefulness of what they were doing for most people who were at risk of HIV. This was worrisome. I just didn't see what would make their arguments work elsewhere. Presenters needed to argue why their claims were relevant. Major assumptions were being made about adherence and adherence over a lifetime. Speakers were also making jumps from scientific outcomes to policymaking and guidelines. I wondered if having the scientific results really justified peoples' competence to make policy. In this particular panel, discussion of the treatment cascade was interesting. But there was not much discussion to explain why at each point in the cascade a percentage of those on the cascade were lost and what was going on to cause this at each step. This was interesting to think about: If this described the situation in the USA with its massive resources, what might it suggest in much poorer countries? What would their cascade look like, and how would one explain the drop-off at each step? Interesting ... I was not sure how at the same conference discussion of the goal of 15 million by 2015 under treatment could make sense taking into account the causes and implications of drop-off in the

cascade as shown in another panel. Did these people talk to each other? ... I had just seen Rachel (Deacon, my PhD student at the time) who also shared her frustration about the conference. She was surprised about the lack of social science input, but even more so by the lack of social science understanding. I had to say 'welcome to the club!' (July 2012).

In South Sudan, we were going to go back to the refugee camp in Ezo as we had agreed with the administrator there. They had recommended we also go and see a guy in the international NGO who was dealing with the health issues in the camp. That same morning, we were told by the person who brought us here that on the other side of the road was the Central African Republic, literally over the road from where we were then sitting. The Congo [DRC] was a bit further away, but it was also within walking distance, as the local market was on the border there. The camp itself was a bit further away from the square, perhaps a few miles away in the bush. It had a reception area and immediately I noticed that against the left-hand wall, there was a box, clearly for condoms. They said they put the supplies there and that anyone could come and pick them up when they wanted. I could not stop myself from opening the box to look inside; it was empty, and the administrator said with a little smile, 'we are waiting for supplies'. The camp appeared to be managed by International SOS, an international NGO, on behalf of UNHCR ... The day before, we had noticed that there were a lot of people around. On this day, we first interviewed the international NGO guy who dealt with the health in the camp. He was friendly. He said that often with patients, nutrition was a problem so that they provided it particularly to children. He said that as all refugees were registered they were able to keep track of them but that sometimes they would see new sick people in the camp and that these were not registered. It was clear from his remarks that there was a lot of health-/AIDS-related movement between Congo and the camp. He said that HIV numbers were generally high and that most people were tested 'once they arrived in Ezo and realized this, but some also arrived knowing that they were HIV-positive had but never had any treatment in the Congolese side' as resources in the conflict area were very limited. For tests and other clinical interventions, they needed to go to the hospital in Nzara (about 2–3 h drive from the camp depending on the road and weather conditions). He added that 'every few months we do awareness activity and get them to test'. After this conversation, I thought what he said must be correct as in the camp it was easy to talk about HIV and AIDS; people were very open about their status and needs even when others were around. In conversation, a number of people said that 'it started in Congo' and that they learned they were 'HIV-positive here'. Talking to a group of women in their mid-20s to early 30s, one of them said that 'there are problems with [the] hospital and its distance from the camp'. She said that she went to the hospital but never got proper medicine for what she needed, just always the same pill for headaches. But then two others began to talk about the HIV medications and care they get in the camp and the fact that they talk about this to their husbands. This was fascinating, as the two clinics they were talking about were so different: The first person was talking about the original clinic in the camp dealing with health in general, but which had now been moved away from the camp, while the other women were talking about the HIV

clinic to which they were taken regularly for their treatment needs. The difference between these clinics was something to think about... (December 2012).

I met the main fundraiser guy in Geneva (Switzerland) to discuss whether it would be possible to raise some funds to support some of the main social science-related activities we were planning for the Melbourne World AIDS Conference in 2014. He was very direct and said that the funding of the conference is generally difficult and also that they realized that people 'don't want to fund social sciences; they don't know what it means in relation to AIDS'... (November 2013).

After asking a few people, we managed to set up a meeting with a local HIV-positive people's community organization. I met with two reps in their office, a flat in a block of apartments not too far from the centre of Yangon (Myanmar). They talked a lot about access issues and the complications of having different organizations providing treatment and also about the existing unmet needs. They said that 'most of the time there is a service quality difference between International NGOs (INGOs), local NGOs and the national programme. The national programme provided only treatment; some national NGOs provide food package and counselling space'. What was interesting was that when talking about stigma, they made reference to issues such as 'the work place, in schools for children, for housewives and at the public hospitals'. After asking a few more questions about the groups that were most stigmatized, they talked about men who have sex with men (MSM). I got the impression that this was not an easy thing even for this group to talk about: 'MSM has high stigma. In hospitals they don't want to give MSM [a] proper examination. For MSM, it is also difficult to have access to ARVs. These are issues for medical staff. They give reasons like *they are MSM; IDUs are not stable people, so they cannot control themselves*. They don't want to deal with them [MSM and IDUs (Injection Drug Users)]. They are not ready to change their minds'. This was in line with what I heard later the same day from a doctor working in a medical INGO. He said access to MSM was 'very, very difficult – as access to them to conduct research was very mediated. MSM do not trust people to keep them anonymous'. I also had a discussion with an international AIDS expert who directly said that 'MSM is a problem. MSM is a problem because, normally, talking about sex is not accepted. Sex is an issue in a very conservative society. They just don't talk about it. They also consider MSM from the perspective of the receptive partner and also more in relation to transgender. Policy intake on this issue is very difficult; the research is difficult'. Interestingly on that same day, everyone talked about the difficulties of reaching groups, difficulties that were clearly based on existing norms and values. Compared to MSM, sex workers were more visible, but they also faced similar problems in relation to service access because people were not interested in their issues. One NGO leader said that she had taken some people from the parliament, lawyers, to Melbourne for the AIDS Conference for them to see how other countries worked with sex workers and that it was helpful in the end ... but it was not very clear how all of these would relate to the imminent political change in the country. Would local sociocultural prejudices change if the regime changes? According to some, no not really (October 2014).

The return from every field visit is crowded with anxieties and questions about the issues observed. The difficulty is to see how some of these dynamics can change to allow people to live the lives they want to lead. This always requires one to think about what needs to happen in terms of the politics and policy within which AIDS is approached. However, I have also observed over the years a gap between diverse experiences of HIV and AIDS in the field and the discussions of HIV I have been involved in at the international level while participating in conferences or discussions with key policy actors. In these discussions, I have always thought that people are very dedicated and driven to tackle the disease wherever it occurs. At the same time, I have always thought that ordinary people live their lives and experience HIV in particular ways. These field observations have also taken place in what gradually has become an area of study, now commonly known as global health. In this field, HIV has become an archetypical global health issue. This created for me an analytic question: What is global about HIV in the lives of people I have observed in the field? It is true that their lives intersect with the more international dimensions of AIDS, but via a series of encounters that does not represent the entirety of the way people live as observed in my fieldwork. In poorer countries, people may experience the global aspects of AIDS through NGOs, clinics, the media and more gradually through schools. But these encounters do not represent the entirety of infected and affected persons' experiences with HIV. However, I have also come to realize that, for the international community of scholars and policymakers concerned with HIV, these encounters have come to construct who infected and affected people are and what their lives are about. Through an HIV and AIDS lens, different lives are thereby brought together as a community, a community of concern and for policy action.

Global AIDS as Field of Research Interest

The brief field notes above identify some of the different dynamics at work in diverse places, yet it is also possible to observe within them a common approach to dealing with AIDS overall. What I will call the Global AIDS system facilitates the focusing of research and public attention on particular parts of the world and particular topics. These then become different issues of concern for Global AIDS policy. Throughout this process, however, the Global AIDS approach itself escapes from being researched as a frame of reference or as an institutionalized process in which organizational actors develop policy priorities that affect people's lives deeply as part of their HIV-related experience. So, how best do we think about Global AIDS as a part of people's experience of HIV/AIDS? This question and the observations that led to it highlight a key issue, namely, how does the Global AIDS system differentiate the 'field' – into research and into HIV and the expertise that produces priorities, policies and plans for the future. By focusing closely on this differentiation, the field can become a context of discovery, a mini-laboratory if you like. In this book, I argue that this process of differentiation – between science and

application – is a problem and that this latter setting should be opened up for research as a legitimate part of HIV- and AIDS-related analytical questioning.

Another issue that I have encountered concerns the analytic tools available for thinking and understanding research observations obtained from different sites: How best do I observe the specific and then derive their implications for policy thinking? The answers to these questions are nearly always those already provided by the Global AIDS system in the form of policy-relevant conceptual frameworks. This creates further questions: What are the ways in which the ‘givenness’ of this system frames the problem and people’s lives? Are the given analytical orientations relevant, who are they relevant to, and do they allow people’s experiences and voices to influence and change the policies that target them? So, the question for me is not only about the policy impact of the Global AIDS system in its organizational aspects but also about the way in which it conceptually frames thinking on AIDS in relation to real people’s lives. In order to unpack these issues, this book focuses in on the knowledge production processes that are an essential part of the Global AIDS system.

The book’s metatheoretical orientation is closely related to my earlier work (2006). In that work, I developed a specific analytic lens to think about HIV and AIDS, which moves us away from looking at the problems of HIV from the point of view of the international organizations that try to align people’s responses to international AIDS policies. Instead, I argue that policy thinking should start from the way in which the disease is experienced by real people in different contexts of their lives. Karin Flikschuh (2014: 1), a political theorist, advocates for ‘philosophical fieldwork as a possible corrective to our current state of ignorance regarding the thoughts and views of distant others in the context of global normative theorising’. Her writing is akin to my own thinking. For her, fieldwork is a conceptual engagement in relation to distant others. She writes:

[By] ‘distant others’ I do not mean the ‘global poor’ but our academic peers who work within moral and political contexts distinct from ours and whom we tend not to consult in our global theorising: distant intellectually as much as geographically. (2014: 1)

This book is an attempt to provide a way of thinking about Global AIDS and its normative framework from the position of being an intellectual other than within the global system. This orientation arises, similar to Flikschuh, from a concern with the continued emergency-logic which aims to ‘solve’ the AIDS problem in a constant present that does not allow for theoretical enquiry about the nature of the Global AIDS itself and one which leads to the establishment of particular ways of doing AIDS as ‘a value system’ (2014: 2). The way in which this process is naturalized as an intervention in people’s lives requires questioning.

In this book, then, by developing an analysis on the relationship between the institutionalization of particular policy processes and actors and the knowledge production process in general, I am interested in the implications of the Global AIDS lens as it seeks to make sense of different people’s lives in different places. This requires us to consider the implications of this process for those living lives that intersect both with HIV and with this global system of policy, which I call Global

AIDS. This is a vast area for research, and no single book can provide a comprehensive or definitive answer to these questions. The aim here though is to think innovatively, outside the box, and to raise questions that provide new ways to do research on HIV and AIDS. The analysis is based on multiple sources of knowledge based on field experiences, participatory observations from within the global policy process on implementation issues, other forms of research and the existing literature. The Global AIDS system has major implications for how people living with HIV sustain their lives and achieve their aspirations. A driving question, however, is whether the Global AIDS system as it has emerged over time has the expertise and the capacity to maintain change in its engagement with different people across different places. As I will show, under the impact of need for sustainability, this is far from an abstract question.

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