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Enabling Geographies? Non-Governmental Organizations and the Empowerment of People Living with HIV and AIDS

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Some people accept me, but some people still don't. Sometimes people abhor (*chang*) me. And [sometimes] they display an attitude of discrimination (Ton, a PLWHA living in Chiang Mai Province, Thailand, cited in Del Casino 2000: 256).

Disability is a form of social difference whose marginality is confirmed both by the oppression which disabled people experience and by its invisibility within the concerns of social sciences, including human geography (Gleeson 1997: 199).

Introduction

While early investigations of HIV and AIDS by geographers focused on the spatial distribution and diffusion of these phenomena from a spatial science perspective (e.g., Gould 1993; Lam and Lui 1994; Pyle and Gross 1997; Shannon and Pyle 1989), in recent years geographers have become more concerned with the socio-spatial configurations of HIV and AIDS (Brown 1995, 1997; Craddock 2000). In particular, geographers have examined the day-to-day experiences of people living with HIV and AIDS (PLWHA) in relation to social activism, health care needs, and social welfare services (e.g., Brown 1995; Chiotti and Joseph 1995; Del Casino 2001; Takahashi 1998). The interest in the socio-spatial dimensions of living with HIV and AIDS also coincides with the growing interest in the geographies of disability (e.g., Gleeson 1999). In some cases, these two areas of study have been interrogated in concert (Takahashi 1998; Dear et al. 1997). As a result, geographers have examined how disabilities, such as AIDS, are not only physically disabling, but socially disabling as well.

Constructed through discourses of difference, disabilities such as AIDS are mediated through their relation to local and global socio-cultural and political economic processes (e.g., capitalism, biomedicine, patriarchy, etc.). In addition, the socio-spatial constructions of disability are mediated through organizations (e.g., hospitals, schools, churches, families, activist organizations, etc.) (Del Casino 2000), whose spatialities and constructions of disability also differ in relation to broader socio-cultural and political-economic processes (Foucault 1973). In some cases, organizations reify disabilities by forging social and spatial boundaries between disabled peoples and their `others.' On the other hand, some organizations actively work to challenge the ways in which disabled people are marginalized in society. PLWHA, like other disabled people, must negotiate a myriad of organizations from the time when they first learn they are HIV positive to the moment before their death when more often than not they are bedridden. Therefore, understanding the ways in which disabilities are constructed and negotiated through organizations is an important question not only for geographers, but also for other social scientists working in the area of disability studies.

In this essay, I focus on one organizational form, non-governmental organizations (NGOs) and their work with PLWHA in the Upper North of Thailand. In so doing, I want to explore the ways in which NGOs work with, and for, PLWHA to challenge the disabling effects of HIV and AIDS that are often

manifest in a variety of organizations (e.g., the public health care system, the community, and the family). In the following section, I offer a brief theorization of organizations in order to provide a starting point from which we can examine organizations (see Del Casino et al. 2000 for a detailed discussion of methodological frameworks for the study of organizations in geography). Second, I provide context for the study of non-governmental activities in relation to the growing AIDS crisis in Thailand. Finally, I offer a brief explication of the theoretical elements through one ethnographic example from fieldwork conducted in Chiang Mai, Thailand, during which time I collected in-depth data on one key NGO, AIDS Organization, and its work in several rural districts.

Organizations as Objects of Analysis

What do we mean when we deploy the term `organization'? First, organizations are fields of inquiry which are messy, unbounded, networks of socio-spatial relations. As such, they are not simply empirical objects fixed in space by the bricks and mortar that constitute their walls (Klausner 1993). Instead, organizations are constructed through the discursive practices of social actors who choose to define the boundaries of one organization in relation to another: they are constructed out of their engagements with others, be that a target population or other organizations (Natter and Jones 1997). A non-governmental organization in Thailand, for example, claims its identity as `non-governmental' because it is believed that the organization is not embedded in a State-centered development agenda which works on the side of the urban-based industrial sector and against community-centered approaches that empower PLWHA, and others, to organize their own outreach (Costa 2001; Del Casino 2000).

Second, since the boundaries of an organization are fluid, the day-to-day practices of organizational actors cannot be examined outside the layers of context and flows of socio-spatial relations that mediate their work (Appadurai 1990). Organizational actors are subject to the same discourses of gender and class or to the flows of capital to which other actors are related. At the same time, the fluidity of boundaries exposes tears that exist in the socio-spatial configurations of power, allowing social actors to play those tears to their benefit. What this suggests is that the process of constructing spaces as spaces of power is never complete. This is not to say that those in power do not have the ability to close down or shut off access to the tears - through the process of temporarily fixing organizational boundaries through the deployment of hegemony (Natter and Jones 1997) - but that tears can be exploited. Boundaries between organizations are blurred and often ambiguous. Thus, for many PLWHA it is often difficult, and perhaps unimportant, to distinguish between ongkaan rat (government organizations) and ongkaan ekachon (private organizations).

Third, organizational relations are antagonistic, signaling the failure of organizations to secure `difference' (Laclau and Mouffe 1985). Since the strategies of creating social identities through organizational politics can only ever be a partial process, social categories remain contested and open. This is true because, as Laclau and Mouffe (1985: 125) argue, "...the presence of the `Other' prevents me from being totally myself. The relation [between organizations and individuals] arises not from full totalities, but from the impossibility of their constitution." It is argued here, therefore, that through antagonistic socio-spatial relations, tears appear through which resistances to dominant discursive practices are coalesced. One could say that antagonistic social relations metaphorically `rip open' the sutures that are designed to fix and assign meanings to particular organizational spaces and the actors that travel through those spaces. Antagonisms existing at the boundaries of organizations afford social actors the opportunity to expose tears (i.e., opening up moments of access to needed services) and push the margins of organizational structures.

Finally, the extent, and size, of the tears in organizational boundaries varies from organization to organization and in relation to the practices of organizational actors. As government officials in Thailand, public health care workers must negotiate not only authoritative practices that are constructed through biomedical discourses (Foucault 1973) but government policies as well (Del Casino 2000, Chapter Four). In some cases, public health care workers invoke discourses of authority in order to regulate the health care of client populations (e.g., in order to control the

movement of AIDS-related funds in the locale). In similar ways, Thai local administrative officials, who are the link between communities and government resources, may be more interested in maintaining patrimonial hierarchies between themselves and their constituencies than in opening up the locale's decision-making mechanisms to community groups (Hirsch 1990). Thus, when new structures of health care outreach, such as support groups for PLWHA, are suggested and implemented by PLWHA, NGOs, and concerned public health care workers, the extent to which those organizations are able to create new networks of socio-spatial relations for PLWHA depends on local relations of power and authority.

Organizational Politics and the Geographies of AIDS

The spread of HIV and subsequent increase in the number of AIDS cases globally has brought to the fore the need to address both prevention and care issues. In most cases, governments are unable, or unwilling, to provide adequate prevention outreach or health care services for PLWHA. As a result, non-governmental organizations (NGOs) have grown in importance as a key part of the service economy for PLWHA in many contexts. In Thailand, where there are an estimated one million HIV positive people, NGOs provide a number of critical preventative, health care, and social services for PLWHA, their families, as well as the broader communities in which PLWHA live. This is most clear in the Upper North of the country (Fig. 1) were it is estimated that one third of total HIV cases currently reside and a substantial amount of AIDS-related funding has been targeted by both the international community and the Thai government (Del Casino 2000, Chapters Three and Four).

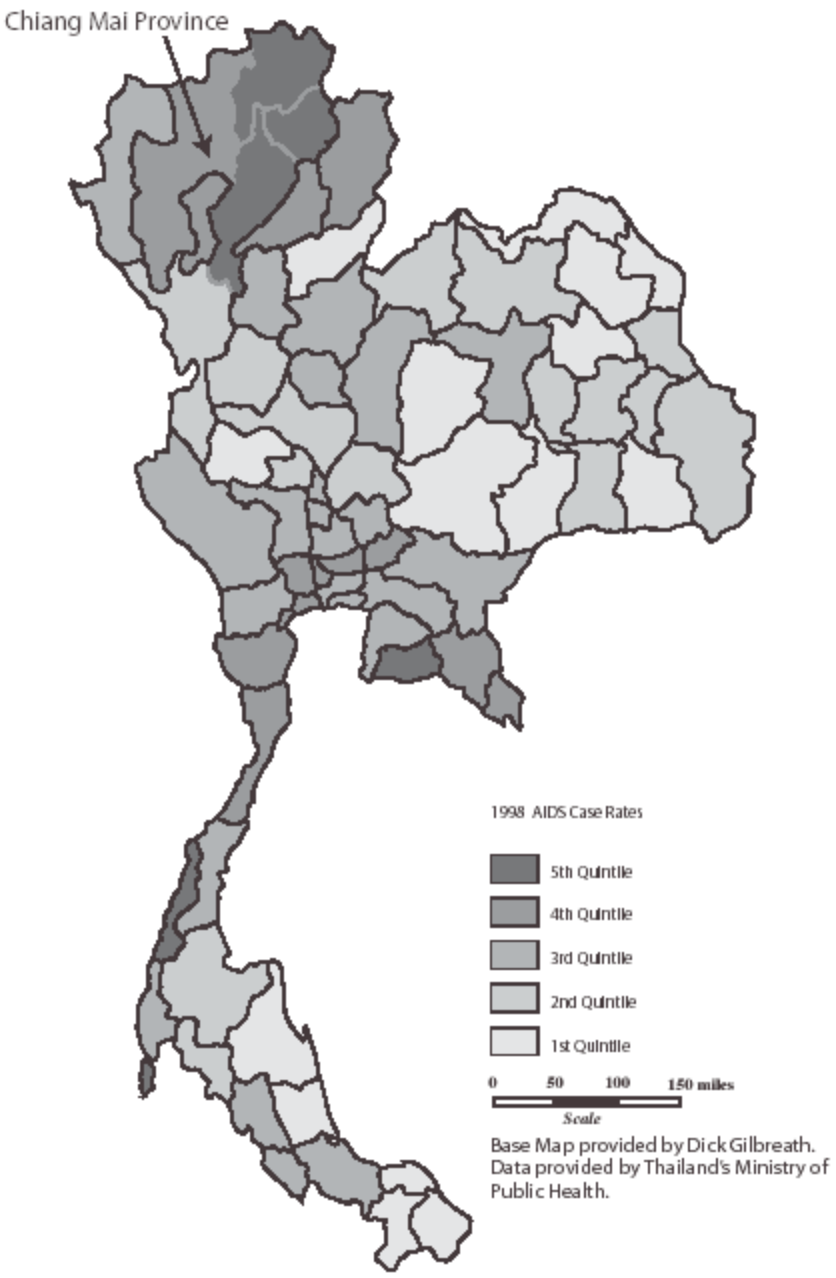

Figure 1: AIDS Case Rates for Provi nces of Thailand, 1998.

Since the early 1990s, the number of NGOs working on AIDS-related issues in the Upper North has also grown. By the late 1990s, there were over fifty organizations operating in the region. AIDS Organization, which began its work in the early 1990s, has grown along with the amount of available funding in the region for AIDS-related activities. When it was founded there were only three full-time staff. By 1999, the total staff had grown to sixteen full- and part-time workers. AIDS Organization's main charges have been to provide PLWHA with opportunities to gain access to needed social and health care services - including alternatives to biomedical treatments for HIV disease and AIDS-related illnesses - and to assist PLWHA in organizing their own support groups. In the case of the latter, the goal of organizing PLWHA support groups coincides with AIDS Organization's broader goal to provide rural poor with opportunities to participate in the decision-making structures of local

government organizations, including health stations, community hospitals, and or bor tor (tambon (sub-district) administrative organizations). AIDS Organization's goals also coincide with the broader goals of AIDS-related NGO movement in Thailand, which is to challenge the negative constructions of PLWHA as `disabled' (for further discussion of the social construction of PLWHA and HIV/AIDS in Thailand see Del Casino 2000, Chapter Three; and Lyttleton 2000). AIDS Organization thus works to enable PLWHA to take charge of their own health care regimen and to open up opportunities for them to participate in the socio-spatial organization of Thai society as active citizens, not simply as passive recipients of health care and social welfare benefits (Reeler 1996).

AIDS Organization, like many other organizations in the Upper North of Thailand, also works through a framework of PLWHA empowerment to increase the social and spatial mobility of PLWHA. One of the mechanisms that AIDS Organization has used to that end has been the PLWHA support group. PLWHA supports groups in the Upper North, of which there are now more than 200, have been initiated by PLWHA themselves, by NGOs, and by the public health sector as a means through which to increase PLWHA access to needed services (psycho-social and medical). In all cases, they are considered their own entities, termed in Thai ongkaan chumchon (community based organization). The extent to which PLWHA are empowered to facilitate their own outreach efforts, however, depends on the interests of other organizations that work with, and through, support groups. In some cases, public health care administrators have tried to maintain strong control of PLWHA support group activities.

As Hirsch (1990: 162) has argued government officials sometimes help organize ongkaan chumchon in order to gain "access to the village population" and to extend "the pyramidal hierarchy [of power and authority] down to the village level." In so doing, public health care officials may be more interested in expanding their own base of power than in providing PLWHA with access to decision-making structures of the public health care sector (i.e., health care officials do not always support transparency). In other cases, PLWHA have organized themselves without outside assistance and thus have more autonomy over their group's agendas and daily practices. NGOs, which often operate through a discourse of local autonomy, see support groups as vehicles through which community members are empowered to participate in the historically closed spaces of public administrative life. Ironically, being a PLWHA, which can be socially and physically disabling, can also provide a point from which individuals who have historically sat outside local power structures may now participate in the political decision-making mechanisms of the State.

PLWHA support groups are also potential vehicles through which PLWHA can participate in their own health care regimens, thereby enhancing their own economic and social well being. Since PLWHA support groups sit at both the margin and center of governmental and non-governmental organizational outreach, they are also subject to the flows of various discursive practices emanating from a number of sites. As such, PLWHA have an opportunity to engage what it means to be a `person living with HIV and AIDS.' As social actors involved in their own outreach (i.e., consumers) and not passive recipients (i.e., patients), PLWHA who are organized have the opportunity to transform the social and spatial boundaries that exist between the disabled and the enabled. They also have the opportunity to blur the metaphorical and material lines that exist between the 'healthy' and the `ill.'

The process of enabling PLWHA and challenging rigid discourses of disability, however, is never complete. In the next section, I discuss the ways in which AIDS Organization's outreach impacts the ability of PLWHA to have access to and participate in the construction of needed services. I do this through an examination of one PLWHA's role as a member of her local PLWHA support group, a group initiated with the help of AIDS Organization in 1997.

Enabling Geographies

I first met Aun, a PLWHA living in Chiang Mai, in 1997. She was, and continues to be, the president of her local support group. As a member of the PLWHA support group, Aun has learned to not only

negotiate the complex organizational structures of health care and social welfare in Chiang Mai province, she has also become an activist in her community. She speaks with local youth and participates in round table discussions with NGO representatives, health officials, and other PLWHA on the care of PLWHA in her tambon (sub-district). In the case of the former, Aun explains her role:

I go to advise [youth] not to be associated with this issue [HIV/AIDS]... I tell them `you should not pai thiaw' (go out partying)... I tell them how I can not work hard.... I will have to leave my child with my younger sibling [after I die]. Sometimes my child would like sweets and she asks me to buy them for her, but I don't have the money for such things... I have to find money. My ability to make a living continues to decrease.

Aun provides information on living with HIV and AIDS to people in her tambon. Through her educational outreach and advocacy she illustrates that PLWHA are not `helpless victims,' but are productive members of society who have information and experiences to share with other in the community. Her work as an HIV/AIDS educator also addresses other segments of the tambon population - such as parents and teachers.

In the beginning there was a problem of discrimination at the local nursery school... There was a training session on HIV/AIDS for the teachers. Really it wasn't the teachers that discriminated, but the parents of the other children were afraid that their children would contract [HIV] from my child. But now there isn't a problem.

Through the training, teachers have been able to more effectively educate youth and parents about basic HIV epidemiology, in the process reducing fear and stigma against PLWHA and their children. Aun has also participated in AIDS awareness projects that used elementary-aged children as educators. In one case, the PLWHA group, along with the tambon administrative council, the health station, and mor muang (village healers), held an AIDS day rally in conjunction with students from one of the local schools. The march raised over 8,000 baht (about US $230) for AIDS-related activities in the tambon.

Aside from her roles as Committee representative and community educator, Aun also has a formal position as a volunteer for a different NGO (Community Action), one that provides her with a small stipend to conduct outreach and collect data on the AIDS situation in her tambon. Aun's job is to visit other PLWHA as well as the guardians of AIDS orphans on a monthly basis and provide them with both moral support and information on outreach programs available to them.

There are several facets to her outreach. Her visits offer people an opportunity to improve their kamlangjai (spirit) through friendship (one literally "gives" (hai) kamlangjai) and thus improve their overall health. The social aspect of the visit, which is accomplished through the sharing of stories (and laughter) and showing others that someone else understands the situation, is a critical part of the outreach program. It is also a chance to broaden the informal membership of the community of PLWHA and those impacted by HIV and AIDS. Through her outreach, Aun tells others about their rights as patients or guardians to basic government services, such as access to social welfare and health care programs; and she discusses other issues, such as the NGO funding that may be available to families in need.

As a PLWHA volunteer in her community and as the president of her tambon PLWHA group, Aun extends the boundaries of health care by making connections between herself, the more fixed spaces of health care (i.e., sites in the public health care system), other PLWHA, and those impacted by HIV and AIDS. She acts as an intermediary between individuals and organizations and her visits provide an opportunity to make connections with other people. She can also chart the progress of AIDS-related programs in the tambon. She literally shares her experiences of engaging her community and the public health care and social welfare sectors thereby illustrating to other PLWHA how to negotiate the various organizational structures designed to assist PLWHA. Moreover, various organizations call

on Aun to provide information on the status of PLWHA in her tambon.1

There is a gap, however, between some of the information she collects and actions based on that information. In one case, Aun visited an older woman (70+ years old) who cares for her ten-year old granddaughter and has no income or experience participating in the mechanisms of the public health care infrastructure. The older woman knew nothing about funds that could provide some support for her grandchild's education, and Aun did not present the older woman's problems at any meetings. Aun did tell the grandmother about the funds available for her grandchild's education at the health station, but she did not alert the health stations about the woman's problems. Rather, she left the choice of accessing the funds to the woman. Aun thus may not always know how to use the data she has collected from other PLWHA to alter the patterns of health care or social welfare in her own tambon. Or, the issue may be one of local power dynamics. Because of the power relationships between state and NGO representatives and most PLWHA, Aun might not feel that she has the authority to speak directly to health station officials regarding other PLWHA.

In Baan Nan in particular, the health station is often seen by PLWHA as adversarial (see Del Casino 2000, Chapter Six for a further explanation). Perhaps this is because the health station worker is more motivated to accumulate social and political capital so that he appears as the authority on health-related issues in the tambon than he is to work with PLWHA (see Hirsch 1990 for a further discussion of local tambon politics). In Baan Nan, PLWHA thus find it more beneficial to engage health station personnel through the PLWHA support group, rather than on a one-on-one basis (see Del Casino 2000, Chapter Six; and Del Casino 2001).

On the other hand, the knowledge and experience Aun gains through her participation in the activities of NGOs, PLWHA support groups, and government-sponsored programs does work to her and her family's benefit. She does not simply consider health and health care as her own problem, but she is very much concerned with the health of her child. She has strong aspirations for her daughter and hopes that she will do well in school - "Studying to a high level" - and get a good job. For this to happen, however, Aun must find a way to save money toward her daughter's education. Because her daughter comes first, Aun is motivated to work a variety of part-time jobs (i.e., paid agricultural work and part-time work cutting herbs for the local mor muang group). Aun is also motivated to utilize the spaces of health care and social welfare when they are beneficial to herself and her family. The PLWHA support group, and their activities, can provide new opportunities for PLWHA such as Aun.

Conclusions

Aun's position as a PLWHA activist (perhaps a word she would not use herself) in her community is possible, in part, because of the existence of competing and overlapping governmental and non-governmental organizational geographies, which have opened up opportunities for Aun to challenge the boundaries of AIDS as a disabling illness. In her case, NGOs, in conjunction with PLWHA efforts, have partially exposed tears in the boundaries of other organizations (e.g., schools, communities, public health departments) and in the culture of fear and social violence that often limits the ability of disabled peoples to participate in the socio-spatial mechanisms of power in their own communities. This is not to say that in all cases PLWHA have been able to gain access to the decision-making powers of the State, or that PLWHA have been successful in eliminating discrimination. Rather, it is to suggest that we cannot think of any organization as fixed in discourse or practice, but instead must understand organizations as containing both emancipatory potential as well as the potential to enforce social and political mechanisms of authority.

Notes

1. It is difficult to say what happened with the money. It was placed in the tambon account for AIDS-

related activities. There was a problem, however, with the distribution of the funds to PLWHA (see Del Casino 2000, Chapter Six for more details).

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