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Nature and Particularities of the Social Mobilization of Cambodian Women Living with HIV/AIDS in the Fight Against the Epidemic

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Abstract:

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The emergence of a grassroots movement in the fight against HIV/AIDS stems from collective activism of PLHIV whose needs are experiences are not being addressed by current HIV/AIDS-related programming. The HIV/AIDS program at the national level sometimes does not reach far enough or it ignores the real needs of PLHIV regarding basic needs and social dislocation. HIV/AIDS is not only a medical condition but also a social phenomenon that caused social problems, such as stigmatization and discrimination, and economic problems, such as a basic needs shortage. Furthermore, the experience of having HIV/AIDS (in the family) often creates tension between PLHIV and non-PLHIV in the community and it is particularly the vulnerable groups (such as single mothers with children or families lacking a parent) that suffer the most. The demographic changes in the incidence of HIV/AIDS indicates that it is precisely these vulnerable groups who have not benefited from national programs for prevention and treatment and whose experiences are actually in contrary to the trend of decreasing transmission. Currently, empowerment programs from local and international NGOs help to advocate for and secure some basic needs for some PLHIV; civil society also serves to encourage policy makers to make considerations for HIV/AIDS-related problems not typically included in public programs. But the limited resources of these programs and the difficulties inherent to addressing more complicated social dilemmas have meant that the scope for adapting new programs has been small. The implication is that crafting an effective and comprehensive response to the HIV/AIDS epidemic will require that public programs learn from and, to some degree, rely on a bottom-up mobilization. The participation of women living with HIV/AIDS in the nascent social mobilization has established that organizing and advocacy can go a long way toward highlighting the evolving problems and solutions of the HIV/AIDS epidemic. There is considerable room for complementary action in combating HIV/AIDS if cooperation and channels of communication can be opened and respected between the public and grassroots sectors.

Keywords: Social Mobilization, Cambodia, HIV/AIDS

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Acronyms

100% CUP	100% Condom Use Program
AIDS	Acquired Immunodeficiency Syndrome
ANRS	Agence Nationale de Recherche pour SIDA (National Research Agency on HIV/AIDS)
ART	Anti Retroviral Therapy
ARV	Anti-Retroviral Drug
AUA	ARV Users Association
BBSW	Brothel Based Sex Workers
CACHA	Cambodian Alliance for Combating HIV/AIDS
CHEC	Cambodian HIV/AIDS Education and Care
CCW	Cambodian Community of Women Living with HIV/AIDS
CDHS	Cambodia Demographic and Health Survey
CPN+	Cambodian Network for People Living with HIV/AIDS
CPU	Cambodian Prostitute Union
CWDC	Cambodian Women's Development Center
ICASO	International Council on AIDS Organizations
IRD	Research Institute for Development
FHI	Family Health International
HACC	HIV/AIDS Coordinating Committee
HIV	Human Immunodeficiency Virus
MARP	Most-at-risk Population
MSM	Men who have Sex with Men
NAA	National AIDS Authority
NAP	National Aids Program (Cambodia)
NCHADS	National Center for HIV/AIDS, Dermatology and STDs
NGO	Non-Governmental Organization
OI	Opportunistic Infection
PLHIV	People Living with HIV/AIDS
PRA	Participatory Rural Appraisal
PWHO	Positive Women of Hope Organization
STD	Sexually Transmitted Disease
STI	Sexually Transmitted Infection
TB	Tuberculosis
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNFPA	United Nations Population Fund
UNGASS	United Nations General Assembly Special Session on HIV/AIDS
WAC	Womyn's Agenda for Change
WLHIV	Women Living with HIV/AIDS
WNU	Women's Network for Unity

Introduction

This paper addresses the social mobilization of Cambodian women who are living with HIV/AIDS (WLHIV), focusing on how it communicates an alternative narrative and proposes alternative solutions for combating the diverse problems brought on by HIV/AIDS. As subjects, this research examines women's responses to the HIV/AIDS epidemic how these can be understood as a forum in which a larger social mobilization is being moved forward. This anthropological investigation was carried out by the Research Institute for Development (IRD) under the supervision of Frédéric Bourdier and Ms. Mom Chanthy.

According to official data, the general incidence and the prevalence of the HIV/AIDS epidemic in Cambodia has consistently decreased since 1991. However, hidden behind this so-called success story are groups who have not been the primary focus of prevention programming during the past two decades. The decreasing rate of infection among the brothel-based sex workers and other so-called high risk groups sometimes takes attention away from the fact that prevalence of HIV/AIDS is increasing among pregnant and/or married women as well as children of infected mothers (NAA reports: 2007). Separating out the overall statistic also highlights the fact that, since the beginning of prevention programs in 1991, women, as opposed to men, are becoming more vulnerable and experiencing a higher rate of infection. According to one report, approximately two thirds (2/3) of people living with HIV/AIDS (PLHIV) in Cambodia are women (Ung, 2007). Even though exact proportion needs to be confirmed, the trend is clear and recent programmatic changes to combating HIV/AIDS in Cambodia already include different targeting priorities for medical and social interventions. The national strategy plan supported by the government and international agencies, particularly UNAIDS, encourages a bottom-up approach, partially to increase accessibility for groups previously left out of prevention programming. In the context of the more top-down prevention programs since 1991, such a change in approach is a significant departure. Now although there is nominally more room for grassroots activism and a stronger involvement from civil society, this new policy is still only on paper and has yet to be explicitly implemented at national and provincial levels.

According to the CCW/CPN+ (Cambodian Community of Women living with HIV/AIDS) Membership Directory, the largest groups active in combating HIV/AIDS are made up of women. They comprise around three quarters (3/4, or 17,375 WLHIV) of the total CCW/CPN+ membership (24,150 PLHIV). Many of the participants are women working in Self Help Groups. The involvement of these women, many of whom become capable "activists" in the fight against HIV/AIDS, is supposed to represent a key component for any improvement of the response to the epidemic in Cambodia. A main focus of this report is to examine the diversity of views brought to the table by women activists and to privilege their views on the evolution of HIV/AIDS issues, particularly basic needs and social stigmatization. Thus, this research draws attention to the idea that the emergence and existence of a grassroots mobilization of women living with HIV/AIDS is not, by itself, a solution to new problems. The new ideas and needs of such a mobilization have to be respected and supported, especially because they may not correspond with the goals and priorities of existing programming. In fact, the priorities of this mobilization may be substantially different, or even contrary, to the human resources and programming of current HIV/AIDS-related efforts. In order for a social mobilization to become an intervention, participants must have their voices heard, their activities institutionalized, and their needs catered to. Due to the growing scale of the mobilization, there is reason to believe that supporting and learning from such a mobilization could provide effective solutions to the emerging problems of people living with HIV/AIDS.

Research Methodology

Objectives and Research Subjects

The purpose of the research is to concentrate our attention on the factors facilitating the emergence of the social mobilization of women living with HIV/AIDS and the new viewpoints and issues raised by such this mobilization. I am working on the premise that the spread of HIV/AIDS has caused lots of social and economic problems, in addition to the biological/medical problems, and that these issues need to be taken into consideration complementarily. Of particular importance for selecting informants and sites is the fact that the demographics of the victims of HIV/AIDS have changed since the early 1990s. Many people, primarily men in the early years, have since died and have left behind orphans and partners (often women with children, sometimes also infected with HIV) with little or insufficient support. The awareness about HIV/AIDS has also increased (although perhaps not improved), often leaving PLHIV and their families stigmatized and discriminated in ways that hurt their opportunities to support themselves. At the same time, these diverse and indirect problems have provided fertile ground for organizing and innovative ideas and actions at the grassroots level, particularly among women who are concerned or affected by the epidemic. In order to deeply understand such social mobilization the following subjects are examined:

- The institutions and structures emerging within civil society that are working in HIV/AIDS programs, along with the ongoing government policy toward this sector of civil society.
- The prevailing reasons for the emergence of women grassroots mobilization in the fight against HIV/AIDS. I look at the internal and external initiatives that describe why WLHIV participate and establish groups, community-based organizations and NGOs.
- The incentives that motivate WLHIV and the logistical system which supports their position (financially and institutionally) as important and relevant actors in the fight against HIV/AIDS. In this sub-objective, I specifically examine the constraints and support for the activities of the social mobilization.
- The perception, responses and critiques of WLHIV regarding the national HIV/AIDS program.

Site and Informant Selection

Due to the scope of the study, civil society actors and, in particular, WLHIV grassroots activists (at different institutional levels) and their beneficiaries were the primary respondents. In addition, I focused on the medical staff conducting testing and treatment, outside organizers (NGO members and affiliated persons), volunteers, and female union members.

Two difference sites had been chosen: the first one is Phnom Penh and the second one is in the southeastern part of the country, in Kampot province. We chose the capital, Phnom Penh, because, in spite of a decentralization process, most of the decisions and key actors are from the capital or at least established in some way there, even if they tend to develop a networks and work in the provinces. The site in Kampot province was selected because of the diverse institutional presence of women actors and activists there. There are primarily two institutional levels—first, women belonging to the official public network, and second, people, especially women, who belong to local groups funded by international NGOs that have more diverse development programs that often include HIV/AIDS awareness, capacity of negotiation and encouraging mass mobilization.

Research Methodology

Given the sensitivity of the research subject and the ethical considerations inherent to studying a politicized medical and social phenomenon like HIV/AIDS, qualitative methods were employed for data gathering, with an ethnographic approach used for assessment and presentation of the findings. In general, I focused on the life stories and experiences of those on the ground, and the evolving views of organization workers in the mobilization around HIV/AIDS. In total, the research was lasted 18 months, divided in to three periods: preparation, fieldwork, and the analysis and writing up.

In the two research sites selected for conducting interviews, a snowball technique was used to find informants. On some more anonymous occasions a random technique was required. In total fifty informants were selected in the two sites. Approximately, 25 were identified in Phnom Penh and another 25 in Kampot province.

Much of the research was focused comparing the reality presented in official statistics and reports to the situation on the ground. For this reason, the literature review is focused on sources that enable me to highlight the different views on the HIV/AIDS epidemic and the effectiveness of the response to it thus far. This secondary data was collected and reviewed at the onset of the project and then revisited at the end. These sources include research papers as well as grey literature (research reports, dissemination seminars, newspapers, magazines, newsletters, handouts, and other documents related to the topic)..

In order for primary data to be useful in its own right and comparable in some way to the secondary data (i.e., the reports and statistics), I prioritized fieldwork tactics that allowed me to get a broader picture of the players and their roles in the HIV/AIDS response. Accordingly, data gathering methods ranged from embedded observation to semi-structured interviews and participation in formal institutional activities. The semi-structure guidelines were prepared before fieldwork commenced and included focus on the priorities of this research project and on confirming or contrasting the experiences of informants with the realities presented in the literature (see **Appendix 1**). On average, interviews and individual research meetings lasted 1.5 hours. Tape records and some pictures were used after obtaining informed consent. Participant observation was conducted by joining in some of the daily working and institutional activities of the informants (although at more of a distance when working with sex workers). Through this, I could be introduced to the broader communities which make up the social relations and drive the experiences of the informants. Particularly with sensitive topics, participant observation was also an important process in generating rapport and trust so as to ensure honest responses and a belief in the confidentiality of my work (addressed below also in Ethical Considerations).

Ethical Considerations

In order to respect the informants and the code of ethics elaborated by the National Ethics Committee in Phnom Penh and by the ANRS revised code, I have been very careful to respect both the anonymity and, when requested and necessary, the confidentiality of the persons whether they were interviewed or just observed.

In my experience, most people felt far more comfortable and confident when a guarantee of their security and anonymity was available, which sometimes required generating rapport. However, some persons, particularly those with strong opinions and visibility in the HIV/AIDS community wanted their name and position to be mentioned if their views were published. Their testimonies were, according to them, a way to publically disseminate their points of view. In spite of these informants willingness to be public (which can be perceived as an encouraging step showing the

determination of sincerely engaged peoples), we took the extra step of having some of the most extreme voices sign an informed consent document prepared for this research project.

HIV/AIDS Situation in Cambodia in the last 18 years

In 1999, an estimated 132,300 Cambodian adults were living with HIV. AIDS-related deaths are estimated to have exceeded 10,000 each year since 2000. By 2006 the number of adults living with HIV had fallen to 67,200. From the 2007 Consensus Workshop on HIV Estimates and Projections, the total number of people living with HIV (PLHIV) (adults, plus children) in 2006 was 71,100 people, with adult HIV prevalence being higher in urban areas than in rural areas (2006: urban 1.1%, rural 0.8%). It is estimated that HIV prevalence among the general adult population aged 15-49 years has declined from a peak of 2.0% in 1998 to 0.9% in 2006 (NCHADS, 2007). It is estimated that the number of new adult infections (incidence) declined from 12,700 in 1997 to 1,350 in 2006. The Asian Epidemic Model projections indicate that HIV incidence (new HIV cases), which has been declining among both men and women since its peak in the mid-1990's, will continue declining for the next several years. It is estimated that adult HIV prevalence will decline to 0.6% by 2008 and remain at that level till 2010. The estimate of further reductions in incidence is based on the assumptions of sustained safe behavior and the prevention benefit of lower viral load resulting from treatment. The estimate assumes condom use in most-at-risk populations (MARPs) will remain at 95%. However, even after the improvements past and projected, HIV prevalence in Cambodia is still high compared to other countries in the region.

In looking at the current status of HIV/AIDS epidemic in Cambodia, it is important to highlight which indicators have improved and why, and which indicators might have worsened in the past 18 years. Sexual transmission remains the prime source of inter-family spread of HIV—primarily through promiscuous men who bridge the virus to their wives and other partners. Fostered by gender inequalities favoring men's freedom outside of the house, promiscuity has become somewhat of a norm. The Cambodia Demographic and Health Survey (CDHS) of 2005 found that 9.5% of Cambodian men have multiple partners. In addition to exposure from mistresses and sex workers, the emergences of Intravenous Drug User or Drug User (IDU/DU), Transgender relations and Men who have Sex with Men (MSM) has increased the potential risk, especially for (and through) those who are indulge in multiple risks. The increase in joblessness, and its cause and root in rural-urban and/or cross-border migration, has compounded the risk and geographic spread of HIV/AIDS risks. The increased capability of wealthier men to protect themselves from transmission (even while sustaining higher levels of promiscuity than poorer men) has also meant that the prevalence of HIV/AIDS is decidedly skewed towards poorer families.

Over the past 18 years in the battle against the HIV/AIDS, Cambodia is converging on a more concentrated epidemic, compared to a more generalized one. Females, in particular, represent an increasing proportion of the number of people living with HIV, and consequently, mother-to-child transmission is also growing at an alarming rate. In 2006, 52% of PLHIV were female, up from 38% in 1997. The increased proportion of female PLHIV is partially attributable to a high number of deaths among males, who represented the majority of infections in the earlier years of the epidemic.

Cambodian HIV/AIDS Policy

The successful experiences of the 100% condom use program (100% CUP) has defined the standards and goals for HIV/AIDS programs in Cambodia. Immediately, after the first HIV infections were documented in Cambodia in 1991, the Ministry of Health, with support by the WHO, established the

National AIDS Program (NAP), now the National Center for HIV/AIDS, Dermatology and STD (NCHADS), focusing attention on both STI and HIV/AIDS. In 1995, an outreach program to sex workers was providing a package of educational material about HIV/AIDS/STI and training in skills to negotiate and use condoms in all risky sexual acts. By 1998, a program review revealed that consistent condom use was increasing but was still insufficient and that HIV rate among brothel-based sex workers had risen to an alarming 42.5%. Statistics from the seaport and beach resort town of Sihanouk Ville were even more disturbing with documented HIV infection rates of over 57% among brothel-based sex workers and 3.8% at sentinel antenatal clinics.

Given these statistics and the commitment of local authorities and health staff at all levels, it was decided to pilot the 100% CUP program in Sihanouk Ville in late 1998. Compliance with the 100% CUP pilot was very high and after 18 moths of its initiation, evaluations were showing the successful results that had been obtained in Thailand. HIV prevalence among sex workers declined to just over 40% and a behavioral survey among client groups showed substantial increases in the reported condom use.

The early evidence of success in the Sihanouk Ville 100% CUP pilot project quickly captured the attention of national authorities and in October 1999, Cambodian Prime Minister Hun Sen requested that all "Governors of provinces and municipalities to efficiently apply the 100% CUP countrywide" (Lowes, 2003). In 2001, the 100% CUP had been initiated in an additional 10 provinces. Evaluations and behavioral surveys continue to show impressive declines in HIV and STI prevalence among sex workers and clients groups, along with equally impressive reports of consistent condom use in sentinel groups.

Not only was Cambodia adopting a 100% condom use strategy but other neighboring countries, including Thailand, the Lao People's Democratic Republic, Vietnam and even Mongolia, Myanmar, the Philippines and China. All of these countries are claiming their success story in the fight against HIV/AIDS epidemics under 100% condom use programs.

Prevention has also coincided with some attempts at treatment. Of the 71,100 people aged 0-49 years living with HIV in 2006, an estimated 33,100 were in need of antiretroviral therapy (ART). By 2010 the number in need of ART will increase to 38,600. Providing ART for all those in need could improve survival among persons living with HIV, but only if social and economic barriers are overcome. Based on the provision of ART at current and planned levels, and assuming that other considerations affecting life expectancy do not interfere, the estimated number of deaths from AIDS could decline from 10,000 in 2006 to 1,200 in 2009.

Notably absent from the highly-praised success stories and seemingly consistently improving statistics is the fact that some groups (i.e., non brothel-based sex workers) are not benefitting as readily, or are in fact, worsening during the same period. The implications of these groups on the current demographic of PLHIV is only now after many years becoming apparent. This issue will be explored in-depth in the following sections by analyzing the perceptions and needs of women living with HIV and involved with a social mobilization.

Voices from the Mobilization: How HIV/AIDS Affects Women

As mentioned above, the Cambodia Country Report on Universal Access 2006 reported that 52% of PLHIV were females, up from 38% in 1997. This change in demographic is important in a number of respects. First, underlying this statistic is the fact that many males (including many husbands and household heads) have died, often leaving behind fragmented families, debt or other HIV-infected family members. Secondly, this statistic indicates that at least one vulnerable group in society (e.g.,

wives and children, female sex workers) are replacing a less vulnerable group (husbands and males). These more vulnerable groups are then even less able to deal with the social, economic and medical challenges they often have to face. Some of these challenges, it turns out, are more salient factors in determining well-being than the availability of ART treatment and affordable health care.

The following topics illustrate how HIV/AIDS affects widows and children in the two study sites (Phnom Penh and Kampot Province).

Foods shortage

Often as a result of medical costs, funeral expenses and idle time surrounding the death of a member of the family, it becomes difficult to secure enough food to remain nourished. For those living with HIV/AIDS in the aftermath of a family member's death, nutrition is still more important than medical care, which makes funding for treatment less useful than basic needs for some PLHIV. This phenomenon is equally influential in the city as in the countryside. In response to this emerging need, basic needs support has been forthcoming by some sources but it is not necessarily part of a comprehensive rehabilitation and treatment program. The Global Fund, for instance, providing rice, oil, salt, sugar and other staples to some families who are lucky enough to receive it—but this support is often not enough for PLHIV.

> *"I know I will die someday soon but what concerns me a lot is my little son and I want him to receive a high educated in order to get out of the difficult conditions I face. the main problems affecting my living conditions are discrimination and food shortage. I tried not to work as sex worker many times but I failed because I have no skill and money to start a new business. Currently, I work in the night time as sex worker and I get 8,000 riel per night if I am lucky. This amount of money is for food and the study of my son. I have been living with HIV/AIDS since 2003 and I know that I got this disease when I was working as a sex worker in Toul Kok. Luckily I had a baby before I came to work in Phnom Penh. I ran away from my husband in 2000 because he is such a violent man and does not want to work; instead he drinks alcohol and beats me. I was also cheated by a woman who promised to give a good job. I was sold to a brothel in Toul Kok one month after I started work as garment factory worker.....",* A sex worker in Toul Kok, a member of Cambodia Prostitution Network (CPU), Phnom Penh.

> *"I have received rice relief of 10 kg per month donated by Center of Hope but it was not enough. Now I do not have capacity to work, my life depend on my mother working as a washing laborer, and two of my young children have abandon school to collect rubbish. Right now, 10 kg of rice helps my family a lot. But I heard that [the NGO] will cut the support soon. I worry a lot about this. If so my family will all die",* A PLHIV from Borey Kela, a member of CACHA, Phnom Penh.

As in Phnom Penh, most of the 25 PLHIV that I interviewed in Kampot Province are facing a food shortage and lack of OI and ARV services. Concerning the OI and ARV service providers, I encountered numerous experiences of unprofessional conduct and ridiculing of the patients.

> *"....My husband died with AIDS in 2004 and in that year I discovered I was HIV-positive through a blood test at a clinic in Phnom Penh. However, until now I am still only receiving OI treatment and can not yet get ARV. Now I have no more land to farm because it was sold for my husband's treatment and funeral expenses. Due to my illness people do not dare to come close to me. For daily live my family has relied only on my oldest daughter who works as a salt-worker for a local company, which*

> *can earn her 4,000 riels per day. With this money, we have to pay for all type of family expenses, including some medical care. Even though I get free OI, I have to spend money for medicine to take care of other illnesses that I get. Since 2005 I received 15kgs rice supplied by the Cambodian Red Cross – two time only….",* a woman from Kampong Bay district, Kampot province.
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> *"I don't have enough food to eat since I have not been able to work because of HIV/AIDS. I want food assistances rather than medicines. I will die soon if I have nothing to eat. While I am hungry I do not want to have OI because it makes me feel sick inside",* a PLHIV from Kampot.

Many of my informants, both in Phnom Penh and Kampot, faced the same problem of food shortage in addition to their medical condition(s). For most Khmer families, the male serves as head of family and they are charged with the duty of make money while the female stays at home. Even though the integration of globalization into Cambodia has changed somewhat the typical gender roles in Cambodia life style, the effect is still small even in Phnom Penh. Therefore when the husband dies, those families are immediately faced the problem with income generation and, eventually, food shortage (in addition to the debt they may have accrued from medical costs and funeral expenses).

Stigma and Discrimination

Among the main social problems affecting PLHIV's living conditions is stigmatization and self-esteem problems. The poor awareness about HIV/AIDS by community members often causes discriminatory behavior toward PLHIV, or it causes acceptance to come about very slowly. Even though a generalized knowledge about HIV/AIDS has spread throughout Cambodia, there are still some unreasonable fears (usually concerning worries about transmission) that prevent many in the general population from interacting (fully) with PLHIV.

> *"When I learned that I was HIV positive I did not go out for almost for three months. I turned off my phone and cut all contact with my friends. I did not go to work and just shut myself in the house. During that time, the only thing that I was thinking about was dying. One day I decided to apply for a new job and work in an NGO in Phnom Penh. Coincidentally, this NGO had a program working on HIV/AIDS. I worked with this NGO for 6 months and I decided to open myself up and tell the others that I was HIV positive. Some of them felt sad and had pity for me in the beginning but later on it got back to the normal working life. In my NGO, the idea of WLHIV is normal for them, which is why they encourage me to continue the struggle for acceptance and fair treatment",* a WLHIV working with an NGO in Phnom Penh.
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> *"After I got seriously sick by HIV/AIDS, the people living in my village, including some of my relatives, did not talk to me or my family. When my husband died, few people came to funeral ceremony. Since then my family has been very lonely and isolated. One time, when I felt very distressed, I went to the pagoda but I was not welcome by the monks at all. No monks came to me or wanted to even be close to me. Until now, many of my villagers do not dare to come and talk to me. They come to my house when an NGO visits me, but that is all. Despite this, I still want to survive for my children",* a widow from Kampot working in Self Help Group and a member of CACHA.

Irrational fear of PLHIV by those without HIV/AIDS-related conditions in their family is one of the main stigmas experienced by PLHIV and leads to discrimination on many levels. In addition to the problems generated by social relations outside of the family, many PLHIV experience deep

emotional turmoil that breeds negative feelings directed towards themselves. By internalizing the stigma of their condition, many PLHIV bring the discrimination from the outside into their own homes. Often this is accompanied with self-esteem problems and feelings of isolation that compound the social problems they are experiencing outside of the home.

How a Social Mobilization Responds to the Challenges of People Living with HIV/AIDS

Based on the need to address the larger social reality of PLHIV, the social mobilization has often focused on addressing the problems associated with stigma and discrimination. Because this is less of a technical intervention (like the 100% CUP program) and more of advocacy approach to enabling PLHIV to live better and happier lives, it is necessarily longer term. A broad approach comprising roughly three elements for dealing with the stigma of HIV/AIDS has become part of the mobilization. These elements are:

1. Sensitization of community gatekeepers and generalized awareness within communities
2. Empowerment and participation of PLHIV in grassroots activities
3. Spiritual and religious concern about the issues of PLHIV by Buddhist institutions

1.
An essential step towards increasing acceptance of and awareness about PLHIV is creating a culture of understanding in key figures surrounding PLHIV, especially including neighbors, health care workers, and local authority figures. These figures come into contact more often with PLHIV or have to deal with them in an official capacity, which makes their views particularly meaningful and relevant. Often the discrimination encountered in key figures has to do with the indirect results of an HIV/AIDS infection in the family. Debt from medical or funeral expenses or idle time can lead to poverty and lower status, substance abuse, crime or dangerous jobs. As the pressures and traumas associated with HIV/AIDS increase, the perceptions and support from key figures can fall away, further exacerbating the problems. This is especially the case for PLHIV who find themselves facing discrimination from the health workers they often need the most, or neighbors they used to previously rely on. Naturally, dealing with discrimination of a generalized form in society is the larger picture here, but lacking a larger societal change, there are important people from whom discrimination is particularly harmful (and from whom help and compassion can be particularly helpful). One direct method for sensitizing such community gatekeepers is trainings, through which key members not only break some of the myths they hold, but also learn how to organize on the behalf of PLHIV. Curricula for such trainings (see **Appendix 2** for one example) have been evolving nationally and are often available through NGOs or coordinating alliances of PLHIV.

2.
Many new groups of PLHIV in Cambodia were set up by like-minded people in order to fight against discrimination and to fight for basic needs. For instance, it is not uncommon to encounter small groups set up by MSM and sex workers for the purpose of solving their own problems in a micro way. Normally, such groups start from a small team or group of people who share the same problems and concerns, or the same conditions. As they evolve and coordinate with similar groups or coordinating bodies, their capacity to solve their own problems and contribute to the larger national mobilization typically goes up. In other words, for the small seeds of grassroots organizing present in HIV/AIDS-related groups, networking with other groups or NGOs and Alliances is a very affective tool for raising their voice. See **Appendix 3** for a description of the organizing work of the Cambodian Alliance for Combating HIV/AIDS (CACHA), a coordinating NGO which has become somewhat of a mouthpiece for the smaller groups making up the mobilization.

3.

As the quote above concerning stigmatization confirms, when people are in distress (medical, spiritual or emotional), they often turn to religious institutions for assistance. If assistance is not only unavailable, but discrimination is encountered, the blow can be particularly severe to people already suffering from multiple pressures arising from living with HIV/AIDS. Although religious institutions can suffer from the same lack of awareness as the general population, dealing with this deficit should go beyond educating figures in religious institutions for the simple reason that these institutions can become enormous allies in the combating the spiritual, emotional and social traumas emerging from HIV/AIDS. Buddhist institutions, in particular are increasingly becoming the focus of programs not only aimed at overcoming ignorance and stigma concerning HIV/AIDS, but also of campaigns to harness the political and social will of the pagodas for the good of the people. Campaigns to date have focused on utilizing meditation to reduce psychological and spiritual distress of PLHIV and also encouraging monks to become part of advocacy or community service projects benefiting PLHIV. This is often been preceded by opportunities for monks to attend HIV/AIDS trainings of the variety described in **Appendix 2.** The indirect result is often that awareness about HIV/AIDS is transferred passively to those who are exposed to the pagoda.

Conclusion: The Role of Social Mobilization and the Public Sector in Combating HIV/AIDS

The emergence of a grassroots movement in the fight against HIV/AIDS stems from collective activism of PLHIV whose needs are experiences are not being addressed by current HIV/AIDS-related programming. The HIV/AIDS program at the national level sometimes does not reach far enough or it ignores the real needs of PLHIV regarding basic needs and social dislocation. Currently, empowerment programs from local and international NGOs help to advocate for and secure basic needs for some PLHIV; civil society also serves to encourage policy makers to make considerations for HIV/AIDS-related problems not typically included in public programs. But the limited resources of these programs and the difficulties inherent to addressing more complicated social dilemmas have meant that the scope for adapting new programs has been small. The implication is that crafting an effective and comprehensive response to the HIV/AIDS epidemic will require that public programs learn from and, to some degree, rely on a bottom-up mobilization. There is considerable room for complementary action in combating HIV/AIDS if cooperation and channels of communication can be opened and respected between the public and grassroots sectors. The comparative advantage of HIV/AIDS programs run or evaluated by activists from the community is that they go very deep into the diversity of the problems created by HIV/AIDS—highlighting problems and solutions in the realms of basic needs and discrimination. The advantage of the public sector is in the resources they have and scale of program they can deliver, as well as the capability to shape the public's view on HIV/AIDS and PLHIV.

Policy Recommendations

- Re-evaluate the official statistics commonly used to describe performance of national-level HIV/AIDS programs to consistently consider not only aggregate indicators, but those of vulnerable groups who are falling through the cracks. An understanding of the demographic changes among PLHIV is particularly important for adapting programs to cater to the evolving problem.
- Begin addressing the social aspect of the experience of HIV/AIDS by increasing support for public programs focusing on awareness and myth-busting. In tandem, use the political power of high-profile figures in the political and religious domains to address discrimination.
- Tie in development support from other sources to ensure that basic needs are met in addition to medical needs. A view focused on the overall well-being and risks of PLHIV should become the overriding model, rather than exclusively on prevention and medical treatment.

- Continue to support the grassroots social mobilization by creating space for their views and participation in national and provincial-level dialogues. This can be simplified through coordinating alliances, but should not privilege any specific advocacy group.

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Appendix 1

Semi-structured Interview Guidelines

For NGO Staff

Describe your personal backgrounds; age, place of birth, current residence…..
Life before and after having HIV/AIDS, if applicable..

1. Describe the background of your NGO; when, how and why this NGO was established and who initiated it?
2. What is your NGO's priority purpose?
3. What are your NGO's objectives?
4. Who are your donors? How do they support and cooperate with you?
5. What are your current activities? Who are your target groups and where are you working?
6. Why has your NGO decided to do a project on HIV/AIDS?
7. Does your NGO do advocacy? Why or why not?
8. What are the difficulties that your NGO face? How do you solve those problems?
9. Does your NGO have any networks? If so, how many network and what is their role?
10. Does your NGO have contacts with government institutions? If so, do you have any problem or barriers working with them?
11. Has your NGO changed goals depending on the grant availability? If so, what were the goals that you had changed before?
12. Imagine your donors cut off the funds for your NGO. What would your NGO do? You're your NGO have any other income sources?
13. Does your NGO have any future plans or goals?
14. What do you think about government policies toward civil society working in Cambodia?
15. What is your own opinion regarding civil society?
16. What are the PLHA's (or members, networks, NGOs, donors…..) perspectives toward your NGO?
17. Do you have any recommendations or suggestions?

For Personal Interview

1. What is your position in your organization?
2. Where are you from? What was your job before having HIV/AIDS, after and currently? How serious are your conditions now?
3. How are you involved with this organization? Who introduced you to this organization?
4. What were your challenges at the beginning, and now?
5. Do you think this NGO changed your life and your living conditions significantly?
6. Please compare your situation before you got HIV and now?
7. How many staff are in your NGO… and how many male and female? Why this ratio? How do you select workers for your NGO? What is the salary range in the NGO?
8. How do you feel about your work? Is it humanitarian or just a job?
9. How do you go about mobilizing women in the fight against HIV/AIDS? What is your perspective of those women? Are they committed to mobilizing themselves or do they just want to get the job and solve their personal problems?
10. How do you respond to the HIV/AIDS epidemic in Cambodia? Do you do advocacy?
11. What does advocacy mean? How do you prepare for successful advocacy?
12. Does your NGO form support groups or self help groups? What does support group and self help group mean? And how to form and follow them up? How do they work?
13. Are these groups they getting support from your NGO? If yes, in what way?
14. Talk about the conditions of PLHA in Cambodia in general?

Appendix 2

Training Courses on
PLHIV Empowerment and "How to Respond to HIV/AIDS"
Conducted by Cambodian HIV/AIDS Education and Care (CHEC), 2008

This is a sample curriculum for training courses aiming at improve awareness of and knowledge about HIV/AIDS, as well as improving capacity for combating the HIV/AIDS epidemic in Cambodia. This curriculum is also concerned with creating a participatory environment and community spirit so as to create networks. Therefore, a subsidiary goal is to mainstream awareness of HIV/AIDS and the skills and knowledge useful for organizing around and combating the HIV/AIDS epidemic.

1. HIV/AIDS Management Skills:
    - HIV/AIDS, community education approach
    - HIV/AIDS, problems in the workplaces
    - Intermediate counseling care and support
    - Professional counseling
    - HIV/AIDS TB and ARV
    - Home Based Care
    - Counseling supervision
    - Peer education among youths and behavioral change
    - Human sexuality and sexual health
    - Reproductive health and life skills
    - Leadership and becoming a change agent

2. Facilitator Management Skills
    - Training of trainers
    - Human resources and facilitator coordination
    - Participatory Rural Appraisal (PRA)

3. Project Management Skills
    - Research methods
    - Project management
    - Effective report writing skills
    - Report and proposal writing
    - Participation in planning, monitoring and evaluation

Appendix 3

Sample of NGO: Cambodian Alliance for Combating HIV/AIDS (CACHA)

The Cambodian Alliance for Combating HIV/AIDS was established in 2006 as part of a larger regional mobilization of NGOs focusing on addressing the "real needs" of people living with HIV/AIDS. They are self-described as an advocacy organization with participation from HIV-positive people networks, MSM, transgender, sex workers and their unions, broadcasters, researchers, medical doctors, student associations and civil servants. Its name, "alliance" is an indicator that, rather than a centralized agency with a specific agenda, they are comprised of their members and their respective views.

CACHA's role is primarily to network and facilitate national-level coordination between existing groups whose domain is grassroots mobilization of HIV/AIDS-related activities. They are also instrumental in bringing about certain groups whose function is to fill certain gaps in the activities and capacity in certain areas (or fields).

As an NGO representative to the National Aids Authority (NAA), they have a voice in official discussions concerning HIV/AIDS policy in Cambodia and thus serve as a mouthpiece for their partnering organizations and groups. Funding for CACHA is diverse, with support coming from UNFPA, UNAIDS, WAC, ICASO and ActionAid Cambodia.

In addition to its role in coordination and facilitation, CACHA also sponsors research and reports in order to legitimize the views of the partnering groups and organizations. In general, this allows CACHA to support a larger mobilization by bringing in the diversity of its partners and communicating their needs through institutional channels. CACHA can also serve its advocacy goals as a watchdog of sorts, making sure that policy enacted is truly to the benefit of those intended. One of their current advocacy campaigns entails action research on the effects of the policy environment for entertainment workers. The project is examining the effects of the newly-approved trafficking law (Royal Government of Cambodia, 2007) in order to research appropriate policy solutions and implementation protocols for sex workers.

One of CACHA's main goals is to address the "real needs" of PLHIV. The result is an often surprising focus on general development goals not usually considered specifically HIV/AIDS-related. It is thus through organizations like CACHA that grassroots mobilizations achieve a voice and might become a more substantial part of the national HIV/AIDS apparatus.