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Introduction

This paper presents the findings from an empirical study into the impact of HIV/AIDS[1] at municipal community level in Chiang Mai, Thailand and Kunming and Ruilin in China's Yunnan Province.[*] The study focuses upon young people as a Most-At-Risk-Population (MARP). The purpose of this study is two-fold. *Firstly*, following from global expressions of concern over the risks of HIV/AIDS to yound people, this study seeks to establish, empirically, the impact of HIV/AIDS on young people and the communities in which they live. In doing so, the study seeks to go beyond assumptions that the challenges posed by HIV/AIDS have largely been met by the sustained intervention programmes directed to these two communities over many years. *Secondly*, to identify the continuing challenges being faced; identify and evaluate the character and quality of the policy-making response; and to indicate those aspects of policy requiring further development.

Young people have been identified in successive declarations by global society's primary institutions as most-at-risk with respect to HIV/AIDS. Yet, with some notable exceptions (Lyon and D'Angelo, 2006), there is a relative paucity in the existing literature of empirically-based studies of HIV/AIDS challenges for young people and practitioner engagements at the community level. Young people are particularly vulnerable, both directly and indirectly, to HIV and AIDS and this study evaluates community perceptions of, and responses to, the impact of HIV/AIDS on health education policy and practice for young people. This paper is interested in the questions of how far, and how effectively, global society's concerns and

commitments regarding young people and HIV/AIDS translate into provincial municipalities and local challenges. The study is a response to the 'call to action' by the outgoing UNAIDS Director Peter Piot in 2008. Piot argues that the contemporary challenge for those involved in this field is to gain an overview and closer understanding of the effectiveness of the myriad of policies and programmes for people living with HIV and AIDS, for practitioners, and for government and civil society organisation (CSO) policy-makers, and academics (Piot *et. al.*, 2008).

Specifically, then, the present study assesses the impact upon, and coping strategies of, municipal communities in terms of the HIV/AIDS challenges for young people. There is a degree of ambiguity in defining young people. The relevant literature and the principal intergovernmental organisations in the field use the phrase to refer to different age groups and also make reference to other terms. For example, the terms "youth," "adolescents," and "young people" are often defined variously. The World Health Organisation refers to people between the ages of 10 and 19 as adolescents and the larger age group 10 to 24 as young people. The terms are also used interchangeably (PIP/JHU, 2001: 4). Bruce Dick (WHO) identified age groups for adolescents (10-19 years); youth (15-24 years); and young people (10-24 years) (WHO, 2007: 3). The term young people is used throughout this paper to refer to the 15-24 age group (WHO, 2007: 3). The advantage of this age definition is in a correlation to the established statistical bands of epidemiological reportage on HIV/AIDS. This was the age range discussed in the interview surveys for this study.

Comment [G M1]: Response to question raised by Reviewer 2 about how 'young people' are defined

Existing research on HIV/AIDS has focused on the declaratory and instrumental global health regimes, on national policies and programmes, or on communities defined as specific ethnic or racial groups or geographical districts (Gu and Renwick, 2009; Poku and McGrew, 2007; Poku, Whiteside and Sandkjaer, 2007; Renwick, 2007; 2002). The present paper contributes to this literature by providing new empirical evidence from municipal communities and by providing an international comparison of their respective experiences in East and Southeast Asia. There are a number of assumptions and empirically untested beliefs regarding on-the-ground practices in the HIV/AIDS field based on anecdotal understanding among practitioners. The aim of this research has been to establish an empirical knowledge base for policy and practice by mapping practitioner experiences in a systematic fashion.

Undoubtedly, there have been advances made in countering HIV/AIDS in Chiang Mai and Yunnan Province over the past decade. However, the paper argues that, contrary to assumptions of success in reducing the risk of HIV infection in Thailand's Upper North and China's Yunnan Province, these provincial communities remain at significant risk. This situation exists despite the involvement of the agencies of global governance and civil society, national HIV/AIDS programmes and local interventions in these communities over many years. Social and cultural constructions of HIV/AIDS limit the effectiveness of interventions. Young people living with HIV/AIDS are particularly insecure and fear breaches of confidentiality, stigmatisation, marginalisation and discrimination in their communities. The voice of youth has been heard at the various tiers of HIV/AIDS governance, but policy-making and

Comment [G M2]: Response to suggested revision #5

interventions still limit their participation. A more robust approach is, therefore, required that mainstreams young people in HIV/AIDS deliberative processes in these communities.

The research brought together researchers in Thailand, China and the UK to conduct a study centred on interviews conducted with a range of HIV/AIDS practitioners and development agents in the respective communities. Adopting a human security perspective, the findings presented in this paper indicate that, at the community level, there is partial awareness and variable understanding of global society's declarations on young people and HIV/AIDS, of national aims, objectives and programmes, and of local official responses. Nonetheless, programmes such as the US's President's Emergency Fund for Aids Relief (PEPFAR), the extensive WHO and UNAIDS programmes, and range of international CSO initiatives provide an important mechanism whereby global society contributes knowledge, skills and funds to provincial communities, not least with respect to the sharing of "better practices".

Fundamentally, however, capacity development is about such international development actors working with local practitioners as facilitators or catalysts of indigenous responses to the multifaceted HIV/AIDS challenges facing young people. The findings indicate that, ultimately, it is local resilience and indigenously-driven capacity development that is the key to effective response. In practice, this has meant a greater recognition of the importance of, and participatory role for, young people in the formulation and implementation of state and civil societal HIV/AIDS

policies and programmes. Moreover, despite geographical, cultural and political differences between the Chinese and Thai communities considered in this study, there are significant commonalities in practitioner perceptions of HIV/AIDS impact, in the challenges faced, and in the character of response in the Chinese and Thai communities. This commonality provides a sound basis for enhanced capacity development within and between provincial municipal communities in East and Southeast Asia.

According to the 2008 UNAIDS Global Report, "the global epidemic has levelled off in terms of the percentage of people infected (prevalence) while the total number of people living with HIV has increased to 33 million people globally with nearly 7,500 new infections each day" (UNAIDS, 2008). The impact of HIV and AIDS upon young people has been highlighted by those at the forefront of the fight against the virus for almost a decade. In late June 2001, the challenges of HIV/AIDS for young people were specifically noted at the United Nations General Assembly Special Session on HIV/AIDS (UNGASS). In 2003, in a global population of 1 billion young people, 10 million were estimated to be living with HIV, almost one-quarter of those living with HIV were under the age of 25, and an estimated 5,000-6,000 young people were becoming infected with HIV daily (UNAIDS, 2004). Young people remain a high-risk group for HIV/AIDS today. (UNAIDS, 2008) In 2007, young people aged 15–24 accounted for an estimated 45% of new HIV infections globally (UNAIDS, 2008).

What factors, then contribute to the particular vulnerability of young people to HIV/AIDS? According to the Global Youth Coalition on HIV/AIDS and Global Youth Partners a key factor is poverty[2]:

Comment [G M3]: Response to suggested revision # 14

> "Young people are often hardest hit by poverty because of powerlessness, lack of education, skills and experience and because their specific needs are often ignored by governments. … This means that the majority of young people cannot afford or easily access HIV prevention interventions, basic health care services, HIV voluntary counselling and testing, reproductive health services, condoms, or antiretroviral therapy (ART). Poverty drives young people toward risk behaviours such as sex work and injecting drug use. Youth living in conflict situations and youth who are part of internally displaced populations are further at risk due to a lack of reproductive health services, unmet basic human needs, rape as a weapon of war, and the high prevalence of violence against women." (GYCA, 2005: 6)

In response, global society has sought to respond through declaratory policy statements and by setting specific targets to be met according to an agreed timescale. The most significant of these were the *Declaration of Commitment* made at the 2001 United Nations General Assembly Special Session on HIV/AIDS (UNGASS), and the General Assembly's *Political Declaration on HIV/AIDS* issued in 2006. UNGASS set out ambitious targets on HIV prevention for young people to be achieved by government action. The Declaration specified that HIV infection rates in persons 15 to 24 years of age should be reduced by 25% in the most-affected

countries by 2005, and by 25% world-wide by 2010. Moreover, at least 90% of young people aged 15 to 24 years were to 'have access to information, education and services necessary to develop the life skills required to reduce their vulnerability to HIV infection' by 2005. This was to increase to at least 95% by 2010.

However, the interim global goals for 2005 were not achieved. The United Nations' 2006 progress review concluded that: "Despite progress in expanding access to HIV prevention and treatment, the epidemic continues to worsen, especially among women and young people. Whereas AIDS once primarily affected men, women now represent half of all people living with HIV. … Over half of all new HIV infections are in young people aged 15 to 24" (UNGASS, 2006: 7).

In 2008, the High Level Meeting on the Review of the Declaration of Commitment on HIV/AIDS and the Political Declaration on HIV/AIDS (HLM) concluded that: "Although some countries reported having achieved some of their universal targets, most have indicated that they do not have the human and financial resources to achieve these targets by 2010." (UNGASS, 2008: 9). The Global Youth Coalition on HIV/AIDS had already concluded that:

> "While progress has been made in several areas of the AIDS response, the targets laid out so ambitiously for youth in the 2001 Declaration of Commitment on HIV/AIDS will be unmet by drastic margins; indeed, 7 years later, few governments even bother to collect data specifically on youth … as

> of 2007, only 40% of young men and 36% of young women had accurate HIV knowledge on transmission and prevention." (2007)

Following the HLM, the HLM's Youth Report commented that: "Widespread concern among youth participants noted that despite the recognition of youth issues in the 2006 Declaration and the striking failure of governments on youth indicators, there was not enough emphasis and inclusion of youth issues." (UNFPA, 2008: 7) Consequently, in 2008, the GYCA demanded 'more than a seat at the table' of the HLM (UNFPA, 2008).

This study chose to investigate these wider global considerations at the community level in Chiang Mai, Kunming and Ruili. These were selected because: (i) Thailand and, in recent years, China have been regarded as relative success stories in the fight against HIV/AIDS; (ii) both countries are now experiencing increases in the numbers living with HIV/AIDS in MARPs; (iii) these cities have well-established histories of HIV/AIDS; (iv) and that there is also a significant international involvement in Thailand's Upper North and China's Yunnan Province.

By the end of 2007 there were estimated to be 610,000 people living with HIV/AIDS in Thailand and 700,000 in China (UNAIDS, 2008). According to Thailand's official statistics, the percentage of young women and men who are HIV infected was 0.95% in 2004, falling to 0.45% in 2006, and then rose to 0.64% in 2008 (NAPAC, 2008: 21) Young people in Thailand are increasingly at risk (Podhsita and Xenos, 2009). ESCAP has noted that: 'In Thailand, 50 to 60 per cent of new infections each year are among

people under 24 years of age. According to Thailand's Ministry of Health, both male and female teenagers show "an increasing tendency of having early sexual activities. … Nowadays, teenagers have frequently changed their sex partners." NGOs confirm this trend: "Nowadays, they start having sex at their early age, sometimes even 11 or 12 years old"[35] (N.B. interviewees have been allocated a number and a full citation list is provided at the end of the study). While young people in general are vulnerable to HIV infection, the most at risk are those engaged in commercial sex and those injecting illicit drugs. A new generation of young people sees HIV as a problem largely affecting their elders and estimates suggest that 85% of young Thais do not consider HIV as a serious concern for them. Premarital sex has become increasingly commonplace, but only about 20-30% of sexually active young people is understood to use condoms regularly (Avert.org, 2008; World Bank, 2007). A national plan (2007-2010) was designed to reduce increasing HIV cases among young people. It focused on educating young people about HIV prevention, promoting social values, and encouraging them to participate in HIV prevention activities. In addition, the plan required local organisations to participate in youth-related HIV prevention and control activities (Kaiser Foundation, 2007).

Comment [G M4]: As requested by Reviewer 2

In China, by the close of 2007, the cumulative total of reported HIV cases were to be found in the 20-39 age range, that is, 70% of all such cases. AIDS cases were concentrated mainly within the 20-49 age group or some 69.9% of the total and AIDS-related deaths were also in this age group, accounting for 72% of cumulative deaths (SCAWCO, 2007: 3-4). The principal modes of transmission in Yunnan are IDU and sex work. However, such statements must be approached with caution. One

interviewee in Yunnan noted a survey indicating that, in Ruili, "transmission among sex workers is lower than 'normal' people [i.e. heterosexual transmission]" [10]. This trend was supported by testimony from the Ruili AIDS Office that: "The most worrisome trend is that the infection rate among the non-MARP rate [*sic*] is growing rapidly" [7] According to a recent multi-agency Chinese study, HIV affects injecting drug users most, particularly in Jingpo, Dai, and Yi ethnicities, more than 40% in 7 counties. HIV prevalence rates among female sex workers (FSWs) increased from 0.5% in 1995 to 4.0% in 2007; among men who have sex with men, from 4.0% in 2005 to 13.2% in 2007; among male clients of FSWs, from 0% in 1995-1997 to 1.8% in 2007; among male sexually transmitted disease clinic attendees, from 0% in 1992 to 2.1% in 2007; among pregnant women from 0.16% in 1992 to 0.5% in 2007; and among blood donors, from 0.0075% in 1992 to 0.084% in 2007 (Jia et.al., 2010).

Comment [G M5]: Response to suggested revision #

The Beijing government's "China Action Plan for Reducing and Preventing the Spread of HIV/AIDS (2006-2010)" provided the policy context for a range of preventative and palliative measures (Gu and Renwick, 2008) and international partnerships remain a key component in China's basic health care capacity-building and its drive against HIV/AIDS (Bloom, Liu, and Qiao, 2009). Awareness-raising campaigns in schools and universities and online have run since 2006 (SCWCO, 2007: 17-18; Gu and Renwick, 2008).

The following account outlines the Human Security perspective and qualitative data collection methods applied in this research; provides evidence of community-based responses in the three municipalities; details the research findings in terms of

community impact and governance; makes policy-oriented recommendations; and presents brief concluding comments.

Theory

The research survey in Chiang Mai, Kunming and Ruili addressed a number of key research questions. These were: (1) What is the human and institutional impact of HIV/AIDS on the fabric of these local communities? (2) What are the implications for the sustainability of these communities in terms of issues of governance? (3) How have they responded to the HIV/AIDS challenge? (4) How effective have these responses been? (5) What comparative lessons in terms of 'better practices' can be learned from their experiences?

To seek answers to these questions, a 'human security' theoretical perspective was adopted. For former UN Secretary-General, Kofi Annan:

> "Human security, in its broadest sense, embraces far more than the absence of violent conflict. It encompasses human rights, good governance, access to education and health care and ensuring that each individual has opportunities and choices to fulfil his or her potential. Every step in this direction is also a step towards reducing poverty, achieving economic growth and preventing conflict. Freedom from want, freedom from fear, and the freedom of future generations to inherit a healthy natural environment—these are the

Comment [G M6]: Response to suggested revision # 2. Indented long quotation

> interrelated building blocks of human—and therefore national—security." (2000)

The idea of "security centred on people" gained impetus with various international reports (UNDP, 1994; ICISS, 2001; ICHS, 2003). This momentum has been sustained through initiatives such as the Human Security Network comprising a number of states from around the world concerned with contemporary human security challenges (Renwick, He and Gu, 2009). Much of the conceptual work of Amartya Sen (1999), the annual UNDP Human Development Reports, and the International Commission on Human Security (ICHS, 2003) refocused attention on individual or personal security challenges embedded in various domains of insecurity such as income inequality.

However, as Stewart has argued, human security is also about social groups and the social stability and contributions to individual welfare that they provide. Stewart notes that, in addition to such 'vertical inequality' impacting upon individuals, an important factor in human insecurity derives from 'horizontal inequality' impacting upon groups and, particularly, upon the construction of exclusionary identities and their "fundamental influence on behaviour" (2001, 2), and that 'security is an intrinsic aspect of development' (2004, 2). The substantial literature on identity politics demonstrates processes on differentiation built upon constructed discourses of commonality asserting shared values, ethnic, racial, cultural, historical, or territorial 'roots' that provide a basis for inclusion and exclusion ('us' and 'them').

In terms of HIV/AIDS, the process of group identification operate in a number of ways including, perhaps most obviously, differentiation and exclusion through stigmatisation, assertions of sexual moral impropriety (based upon claimed differences in generational behaviour or upon sexual preference), gendered 'structural violence', or ethnicity (such as 'foreign' migrants as carriers of infection through their cross-border movements or as sex workers). Human security broadens and deepens our conceptual and analytical horizons and has allowed a fundamental redefinition of the contemporary agenda of global society's security to embrace such challenges as HIV/AIDS to individuals and communities (Renwick, He and Gu, 2009):

> "… good health is both essential and instrumental to achieving human security. It is essential because the very heart of human security is protecting human lives. Health security is at the vital core of human security—and illness, disability and avoidable death are "critical pervasive threats" to human security. … good health is instrumental to human dignity and human security. It enables people to exercise choice, pursue social opportunities and plan for their future. … Health's instrumental role is collective as well as personal. Good health is a precondition for social stability." (ICHS, 2003: 96)

Following from this perspective, the explanatory value of human security to this study lies in the development of a research design. This focuses on HIV/AIDS as a personal and community challenge and emphasises human dignity by stressing the pivotal role of good health facilitating personal and collective development. In seeking to understand human insecurities such as stigmatisation and discrimination

Comment [G M7]: Response to suggested revision # 6

often associated with HIV/AIDS, a central concern of the study is to identify and explain the socio-economically generated barriers to the realisation of individual and collective needs, potential and aspirational goals experienced by young people. For Sen, this amounts to "capabilities freedom" (1999). Hence, the study's research questions centre on how young people experience HIV/AIDS in their communities and how these communities engage with them in terms of recognising these fears and insecurities and responding effectively through policy to protect and promote human dignity.

Methodology

The primary instrument of data collection was qualitative interview surveys in China and Thailand. The overall cohort included government health agencies, educational representatives, academics, youth health organisations and local CSOs and representatives of locally-active international NGOs. As a pilot study funded under the Nuffield Foundation Small Grants Scheme, a total of 35 interviews were conducted. The rationale for selection was for community-recognised, active, and sustained involvement in working with HIV/AIDS and specifically with young people. The interview cohort focused on representatives of civil society organisations including religious and Men-Who-Have-Sex-With-Men (MSM) support groups and umbrella organisations for multiple small NGOs; school and college student HIV/AIDS volunteers; provincial and municipal health and HIV/AIDS agencies; specialist health professionals; academics, faith-vased organisations (FBOs) and international NGOs such as Save the Children and the International AIDS Alliance.

Comment [G M8]: Response to suggested revision # . Methodology separated from theory

Comment [G M9]: Response to suggested revision 11 (a)

Comment [G M10]: Response to suggested revision 11 (b)

Interviews were conducted over a period starting in November 2008 with the last interview completed in September 2009. Following preliminary fieldwork interviews in 2008 with NGOs such as 'hdn' (Health and Development Networks) in Chiang Mai and, in Kunming, HIV/AIDS Alliance in China, and consultations with leading local health specialists and academics , it was decided that interviews would be conducted by Thai and Chinese in-country researchers. This would build on local knowledge as well as cultural and political understanding and empathy, and also allow interviews to be conducted in Thai and Chinese without the intermediation of interpreters. Acknowledging the significant sensitivities in the local communities, it was also decided that interviews would be with community organisations representing or working with young people rather than with individual PLWHA. The fieldwork interview surveys in Chiang Mai were conducted by Dr. Warunee Fongkaew and Ms. Warawan Udomkhamsuk in the Faculty of Nursing at Chiang Mai University. Dr. Warunee Fongkaew is an internationally-recognised and widely–published expert in this field. In China, interviews in Kunming and Ruili were conducted by the well-established Yunnan Zhai Wen independent research consultancy organisation. The project team worked closely with the local researchers to establish the survey list of organisations and to develop the survey questionnaire. The project team worked to establish consistency in the types of organisations surveyed in each municipality and the list of questions was standardised across the survey sites.

Comment [G M11]: Response to suggested revision 11(c)

Comment [G M12]: Response to suggested revision 11(c)

The methodology adopted for interviews has been "semi-structured" with an initial framework list of questions being followed with "open-ended" secondary discussion. This encouraged elaboration in "guided conversations" with the interviewer and thus

allowed greater interviewer/interviewee interaction. Interviewees related their experiences in their own words and this opened-up the ideas and contextual influences. The aim was to "to capture meaning, process and context" in responses (Devine, 1995: 137-153). All interviews were conducted in the language preferred by the interviewees. In China, English, Mandarin and local Yunnan dialects were used. In CM, interviews were conducted in Thai and English. All interviews were one-to-one, which was preferred by all interviewees in the survey.

This approach added value to quantitative data "by identifying subject perceptions of their experiences and the meanings they attach to these experiences" (Devine, 1995: 137-153). Interviews were transcribed (Kowal and O'Connell, 2004: 248). Transcription was firstly into Thai or Mandarin and then into English. Transcripts were subjected to repeated readings until themes emerged and an overall argument established. The analysis of interview data followed a 5-step procedure: analytical categories are established; categories brought together in an analytical guide, tested and revised; using this analytical and coding guide, all interviews are coded according to the analytical categories; on the basis of this coding, case overviews are generated; case overviews form the basis for further in-depth single-case analyses/interpretations (Schmidt, 2004: 253). The interpretation of the data is presented in the form of 'descriptive analysis' through transcript extracts (quotations) and commentary.

Community-based responses

There is a richness of community activities underpinned by humanitarian communitarianism designed to enhance capacity-development. The range of responses fall into three categories: network development; peer support; and educational and training programmes.

The myriad of networks includes those initiated by patient groups and focus upon facilitation of health service and medical provision such as Sarapee Hospital's HIV/AIDS Protection Division's group of 12 young AIDS patients aged between 6 and 18 who "care for each other", "share their experiences and opinions" and "when they have some problems in taking the medicine, they will share the way to take the medicine on time"[27]; young volunteers for peer support in schools, universities and out-of-school such as the *Upper Northern Child and Youth Network* in Thailand aiming to "create networks of teenagers in northern Thailand", "encourage collaborations and cooperation among these kids", and "increase potentials [*sic*] in these kids sustainably and successively"[22] and also *CARE-RaksThai's* work with inter-generational youth groups mainly in rural communities with infected and non-infected youth[24]; women empowerment initiatives; MSM support networks such as CM-based NGO *M Plus's* fieldtrips/training sessions for young leaders, provision of a friendship centres and a condom fund, and a Healthy Bars and Healthy Passport Project[26].

Peer-to-peer support: In Yunnan, the *AIDS Care Home (Ai Zi Jia)* has a long-running peer education and capacity-building training programme of 2,700 university and non-university volunteers who also work with many other NGOs[1]. In CM, *Sarapee*

Hospital runs a "Mainstay" initiative in conjunction with SuanPrung Hospital involving junior and senior high school students in six schools. In this training programme young people are selected by vote by classmates and join a two-day training camp to provide student mentors with the knowledge about HIV/AIDS, STD and life skills that they can pass on to their friends[27]. Similarly, *the Christian AIDS Ministry* in CM provides "Sex and Way of Life" leadership camps for young people; fieldtrips; school, church and conference talks, and workshops such as "Pi Dulae Nong" ("letting older youth take care of the younger ones")[28].

Educational and training programmes: In Thailand, the *Thai Youth Action Programme (TYAP)* works with young people in secondary schools through to university to "support the potential of Thai youth", "encourage them to be able to take care of themselves", and to "keep away from AIDS"[29] *AIDSNET* helps organisations find funding to operate their programmes. One such project that gained Unicef funding was a programme generated largely by and for young people entitled 'Right to Know' and run by young people from 2002-2006 through 10 local organisations. This provided knowledge and information for peer-to-peer education, counselling, stage play performances, radio shows, and workshops as well as two books[25]. Taking the idea of using media avenues that chime with the outlooks of young people in order to communicate the HIV/AIDS message more effectively, *Payap University's Student Development Office* took the opportunity of Valentine's day to run an awareness project they called "Power of Love". This involved showing movies at the University's four dormitories and hanging parcels at the front of each room filled with a brochure about HIV/AIDS, STDs, sex and condoms[30].

In China, the *Kunming Family Planning Committee* runs an adolescent health education programme called the Green Apple Project to provide an activity centre offering games, Internet, video and other facilities "so that education on sex and AIDS is provided in a more active, participatory and innovative way" and hence get away from more formalised traditional, school or government teaching approaches[4]. The *Public Health School of Kunming Medical College* has a well-established training and curriculum development provision for sex and HIV[5]. In terms of IDU and HIV/AIDS, *Yunnan Institute of Drug Abuse* has organised in-school training of students and teachers since 1995 adopting a "key facilitator and peer educator approach"[8]. The programme is being adopted more widely and 'mainstreaming' it across the Province on a daily basis within a "Three Sheng" Programme (in Chinese, the three Shengs are: 'Shengming', 'Shengcun' and 'Shenghuo', namely, 'life', 'survival' and 'living'). Significantly, it is being adopted in 'correction centres' with "problem children". Here, interestingly, the students 'are seen as the worst group of children' but, unlike vocational or 'normal' school students, they gave "the fastest response" to the programme.

Community Impact

The initial step in assessing community impact is to establish the quantitative data. The research team found systematic quantitative evidence for HIV and AIDS cases in CM, KM, and Ri difficult to access. In part, this was attributable to the local limitations on monetary and human resources. Interviewees identified the need for

policy to be backed by reliable and available empirical data: "It is difficult to get baseline information as personnel, funding and other forms of inputs need to be in place"[9]. But, in larger part, this was attributable to the sensitivity of the subject in communities thereby restricting reporting; a reluctance of some officials to provide statistical data; and inconsistency in the systematic publishing of local statistics beyond aggregated data. It was also evident from interview testimony in CM that this reluctance was also due to concerns about the impact upon the local tourist economy if HIV/AIDS was perceived to be a problem in Chiang Mai[26].

In Yunnan, issues of designated public security are also a factor[A]. The overall issue of data availability and quality is compounded by additional concerns raised in CM, KM and R interviews that formal statistical databases are not sufficiently maintained due to resource limitations and are therefore out-of-date, are not comprehensive, and often are not made available to local CSOs[24]. One CSO interviewee in Yunnan noted that: "it has been difficult to get detailed and breakdown data. … This is not only an issue for researchers, but also for those working for government-supported research and work of other types."[A] To the interviewee's knowledge, the primary provincial agency has not transparently published a complete and detailed epidemic report.

According to published reports for Yunnan, by the end of September 2008, the cumulative number of PLWHA totalled 63,322 (24% of the national total); the accumulative number of people with AIDS on treatment was 8,602, the overall number of patients was 9,752 (12.5%) and the cumulative number of deaths was

7,015 (20.1) (Li *et.al.*, 2009). Additional official data for Yunnan suggests that, by the end of 2008, the cumulative people living with HIV had reached 65003 (the highest in China) and that estimates put the actual figure to be 85,000–100,000; the total number of people with AIDS in Yunnan totalled 10,883 (the second highest in China); and that the cumulative number of AIDS-related deaths was 7,675. The survey also indicated that a dramatic trend is for an increased number of HIV infections among women.

Secondary research did provide additional data. A 2008 study of 3.2 million blood samples by Tsinghua University's Comprehensive AIDS Research Centre (CARC) put the number of HIV cases at 48,951 and AIDS cases at 3,935 in 2006. In this Report, the key trends in Yunnan between 1989 and 2006 were identified as: (i) 38% of HIV infections spread through heterosexual contact rather than IDU; (ii) IDU accounted for virtually all HIV cases in 1989 but only 40% in 2006; (iii) women and MSM were the fastest growing HIV/AIDS populations, surpassing that of IDU. The percentage of Yunnan HIV cases that women rose from 7.1% in 1989 to 35%. In 1996 the gender for HIV infections was one woman to 13 men, by 2006 that ratio had changed to 1:1.9; (iv) urbanised Han Chinese were overtaking rural minorities; ethnic trends indicated that, between 1989 and 1995, the Dai and Jingpo ethnic minorities in rural southern Yunnan were most-at-risk, by 2006 the Han ethnic majority accounted for 60% of HIV cases. Zhang Linqi, author of the report, noted that: "The high percentage of infected are now due to sexual contact. It has begun to move from farmer, minority groups in rural areas into worker, Han-majority urban settings." (Ostrow, 2008)

Ruili Bureau of Health provided data for Ruili indicating 297 newly-identified positive people in Ruili during the first half of 2008. Of these, 195 were from rural communities; 90 were illiterate and 97 had received education for less than seven years; 116 were from Dai ethnic minority group; and infection for 173 had been sexually transmitted." The current situation in Ruili is that there are positive people under the age of 18, who count for around 10% of the newly identified positives. Among them, they are either very young or near 18 year old. Many of the positives are from Burma."[9] Ruili, bordering Burma, has many Burmese migrants. Many gain income as sex workers. Condom use is low with sex workers able to earn as much as 60% extra by agreeing to sex without a condom. The money earned from sex work income is usually not enough for daily needs and this is exacerbated when an SW becomes ill. Some turn to illicit drugs trading to supplement their incomes until they succumb to HIV/AIDS and/or are imprisoned. In terms of both vertical and particularly horizontal inequalities, this underlines the significance of poverty in the rural/urban divide, poverty in ethnic communities, and the lack of educational opportunities for the poorest in communities as key factors alongside migration, intravenous drug use (IDU), and continuing patriarchal gender relations.

In CM, during the period 1988-2009, there was an estimated 22,547 people living with HIV in Chiang Mai Province with 2,198 adolescents aged 15–24 accounting for an estimated 9.8% of HIV infected people. The Institute for Population and Social Research at Mahidol University identified HIV infected people by age group in Chiang Mai Province. It concluded that there were 94 people (0.4%) aged 10-24 years, 194 adolescent 15-19 years (0.9%) and 1,910 youth 20-24 years old (8.5%). Some 8,377

people were reported to have AIDS symptoms between 1988 and March 2009. In Chiang Mai province, there are 7,579 people currently living with HIV/AIDS including 6,919 adults and 660 children.

The second step in considering community impact is qualitative: 'At the community level, HIV affects how the members of that community live together' [25]. Given the issues surrounding quantitative assessment and also the highly personal nature of the NGO work they are involved in with PLWHA, the majority of interviewees stressed the qualitative impact on individuals, families and the wider communities. Here, resonating with horizontal inequality and community identity formations, the primary impact of HIV/AIDS was held by all interviewees to be what one respondent termed 'social disharmony[28], a fracturing of community values and cohesiveness and 'corruption' of 'cultural charity'[28]. There were some positive outcomes identified, such as greater openness in Yunnan about the virus and sex and MSM and also, in both interview cohorts, a sense of working together to meet the HIV/AIDS challenges. But the survey also revealed a much greater perception of deeper, negative community impact rooted in stigmatisation and cultural influences.

Stigma is still a significant problem impeding diagnosis, treatment and palliative care across the world (Deacon and Stephney, 2005; Deacon, Stephney, and Prosalendis, 2005; Osborne, 2009; Horn, 2009; Rohleder *et.al.*, 2009; Green, 2009; Rai, 2010; Reddy, Sandfort and Rispel, 2010). The AIDS Treatment for Life International Survey (ATLIS 2010) global survey of 2,035 PLWHA presented to the XVIII International AIDS Conference in Vienna indicated that stigma, isolation and discrimination remain

pervasive worldwide. The three most common stigmas to be countered are that: a person with HIV has or does engage in risky behaviour; people with HIV or AIDS should be avoided; and HIV is easily transmitted through normal everyday activities (Horn, 2010). Other studies focusing on Thailand indicate the experiences of women living with HIV/AIDS and their coping strategies in the context of stigma (Julawong, 2009).

Stigma is a significant source of insecurity and emotional stress and depression for PLWHA. Existing research on the social and psychological sequelae of stigma among PLWHA, as in Hong Kong, indicates the relationship of blame to self-stigma is not automatically significant. Rather, self-stigma was found to dampen social support and lead to psychological distress half a year later (Mak *et.al.*, 2007).

The experiences of young people in provincial Thailand and China mirror the global picture presented in the ATLIS survey [21][33][35]. In Yunnan Province, studies of stigmatisation in minority communites such as the Dai have demonstrated that stigma against IDU and PLWH reflected pre-existing cultural, religious sanctions against "deviant behaviours". Stigma generated a vicious cycle of social isolation, marginalisation and addiction relapse which, in turn, served to reinforce styigmatisation and discrimination and undermined the effectiveness of intervention initiatives (Deng, Li, Sringernyuang and Zhang, 2007). A key study of stigma in China, for example, is the *China Stigma Index Report* (UNAIDS and Partners, 2009). The interview evidence from the present study shows that stigmatisation reflects a continuing unevenness in knowledge regarding HIV/AIDS in local communities and

among young people despite high profile awareness campaigns [11] and a consequential difficulty in changing behaviour to reduce risk.

Differentiating from the evidence from studies of HIV/AIDS stigmatisation in Hong Kong (Mak *et.al.* 2006; Mak *et.al.*, 2007), testimony from young people's NGOs in the present study is that fear of being exposed as having HIV is high as are feelings of guilt or "blame" and that, unlike Hong Kong where "knowledge about the disease had no significant effect on stigma", a persistent weakness of knowledge in some community cutlures and in older generations was perceived to be a factor in stigmatisation and discrimination. Many of those who are infected are keeping their illness secret, amounting to 'self-stigmatisation'. According to the NGO 'hdn' in CM: "the fact that some patients prefer to keep their infection status a secret is evidence that there is a serious social stigma going on here in the society. These stigma-affected patients are even too afraid and shameful to get their medical help and decide to die without any treatment"[21].

These findings resonate with the findings of the *China Stigma Index Report* that breaches of confidentiality were attributable to over a quarter of medical staff (26%), government officials (35%) and teachers (36%). Stigmatisation led to over 40% of the interview cohort for the UNAIDS study reporting discrimination including 10% stating that their children had been forced to leave school irrespective of their HIV status; some 26.2% of respondents to the UNAIDS study reported that teachers, once told of a student's HIV status had acted with a "discriminatory" or "very

discriminatory" attitude; one-in-six had been turned-down for employment; many had been refused medical treatment because of their HIV status (2009: 16).

As Visser *et.al.* have shown in the case of two communities in Tshwane, South Africa, to address stigma in a community, an understanding of the nature of stigma in the specific cultural context is needed (2009). In Yunnan, community perceptions of HIV/AIDS are intimately related to practices of discrimination:

> "For a Chinese point of view, to understand HIV/AIDS will encounter barriers. Normal people would see it as a "dirty" disease that only people with dirty behaviours get infecxted. Therefore PLWA are discriminated and distanced. … Psychologically, AIDS is seen as a dirty disease. People would distance themselves from PLWA. … For example, we call SWs "prostitutes" or "mistresses", which are all discriminatory titles. We normally do not reflect why they are SWs. … In the Chinese culture, sex is taboo. Sex behaviours are not discussable. Most people would choose to be silent"[11]

In CM sex is not openly discussed within families as it is regarded as improper. According to all the CM interviews, the principal causal factor is that of culture related to enduring Buddhist values. Interviewees argued that, in Buddhism, sex is a taboo subject and this contributes to a familial silence on sex education[25]. Moreover, testimony from two-thirds of respondents argued that wider traditional values contributed to a lack of knowledge and consequential stigmatisation through

the secondary status and role of women in families and society and the belief that sex education merely promotes promiscuity among young people[4][5].

Hence, HIV/AIDS stigmatisation is often compounded by the sustained influence of patriarchy in these communities. Interviewees noted that, actual behaviour notwithstanding, the idea that women are expected to remain virgins before marriage remains salient and that, for example, pregnant girls are expelled from school. In practice, such patriarchal values mean that there is a continuing familial "separation of responsibilities" and wives do not question men about condom use[23].

There is a resulting lack of 'life-skills' development with few people being regarded as appropriate to turn to for information. Hence, peer group mis-information or absence of information about both safe sex and HIV/AIDS contributes to a cycle of infection in CM. Here, perhaps, it is interesting to reflect on the "social construction of HIV/AIDS". Polgar examines five contending social constructions of HIV/AIDS (medical, epidemic, organisational, moralist and political. Moralist and political constructs, Polgar argues, "at odds over AIDS as a form of social stigma, magnifying many forms of prejudice and discrimination" (2009). In terms of the present study, cultural, religious, generational and ethnic constructions in the respective municipal communities 'frame' and reify HIV/AIDS and young people living with HIV/AIDS, for example, with respect to gender or homosexuality.

Following from such 'framing', the construction of social identities of PLWHA results in marginalisation and discrimination in their daily lives in CM and Yunnan. In CM, for example, workplace blood testing for employment is conducted by some firms and organisations with the threat of a loss of employment, incomes and sustainable lives; a vicious cycle that serves to then further marginalisation and discrimination. Marginalisation and 'horizontal inequality' includes young people. According to a theme common to all respondents, young people in the community are regarded as a source of 'promiscuity and sexual indulgence'[21] and hence of the HIV/AIDS problem itself. This feeling reflects and reinforces discrimination against young people as "scapegoats"[21].

In Yunnan, survey evidence is more mixed. In schools, health and sex education is increasing; just as it is in CM. The Kunming Government is providing training to junior high teachers, but shyness among the teachers to discuss sex make it "difficult to raise the capacity of teachers and trainers involved in health education."[4] Some school leaders are more open and accepting of sex and AIDS education for "there are still reservations."[4]

This account illustrated the janus-faced character of community responses with negative and positive aspects experienced simultaneously by PLWHA. It is, perhaps, useful at this juncture to make some comparison with other sites. Evidence from Sub-Saharan Africa demonstrates a commonality of experience (ECA, 2009: 24-25). The ECA reports survey evidence from South Africa that "the negative orientation to people with HIV/AIDS, even when only exhibited by a minority of community

Comment [G M13]: Resonse to suggested revision # 9

members, and the fear of negative reactions from community members and other persons, is sufficiently strong to provide reason for PLWHA not to be open about their status in their own communities." The South African report indicated that: "Interestingly, support networks did not seem to have evolved, and the individuals living with HIV feel very alone in their struggle to lead positive lives. Social support networks are important for well-being, and a consequence of this finding is that to build a strong support base for PLWHA would be important." The South African experience shows some similarities with that of the sites covered in the present study insofar as PLWHA and MARP such as young people in the latter sites clearly experience loneliness and isolation in the face of negative community attitudes and find difficulty in finding trustworthy and reliable interlocutors. However, whilst the South African experience suggests fragmented or uneven community mobilisation, the evidence from the present study suggests that more progress has been achieved in this respect in CM, KM and R, although more still needs to be done.

The South African study also expresses caution vis-à-vis the appropriateness of mobilisation support from external agencies insofar as this could "undermine local initiatives and ownership. Poorly designed and externally imposed programmes could jeopardize fledgling community initiatives." There is a shared recognition of this danger among those interviewed for the present study. The need for funding meant that some CM NGOs, CBOs and FBOs felt they had to accept "foreign funding" and were unable to "chose between 'bead and steam buns'"[1]. Additionally, some NGOs indicated that external agencies had their own agendas and had, on occasion, left a project and moved on to other interests such as climate change, thereby

leaving existing HIV/AIDS collaborations to wither. Some agencies ask for their model to be implemented by their funding partner in China or Thailand. In one instance, an agency asked for a model drawn from their African experience to be enacted in Yunnan where it was found to be inappropriate and led to 'awaste of resources and time'[1]. Nonetheless, the survey suggested that the external collaborations were largely positive and productive with added weight in national and provincial advocacy, appropriate knowledge transfers taking place, improved monitoring and evaluation (M&E) processes and incremental transition to full local project ownership[22][12].

Finally, the South African study concluded that: "In addition, while the strengths and capacity of local communities is often credited as a substantive means to cope with the multiple impacts of HIV/AIDS, there are limits imposed by wider economic conditions. The difficult economic conditions facing most people prevented communities from offering any or much assistance in … urban and rural locales." Whilst the economic factor certainly resonates with the East and Southeast Asian experience, it is not the case that this has substantially "prevented" the mobilisation of urban or even rural support through civil society networking, knowledge management centres, counselling programmes and performance-based outreach awareness initiatives.

Governance: 'Policies come from grown-ups'

All those interviewed identified the issue of HIV/AIDS and youth as particularly salient and that it is important that discussion on policy in this area is initiated to fill this gap. However, in the Chinese survey, the concept of 'policy' itself was identified as being unclear. Some small and local organisations indicated that they do not normally reflect on policy, they see policy as 'governmental' and characterise it as "big official documents". Official Chinese Government documents often "'require' our collaboration"[15]. This response is grounded in the character of the policy-making system itself. In particular, it suggests something about the evolving political culture in China and the role of civil society where licensing of NGOs remains and a 'semi-civil society' may be said to continue rather than that of Western-style autonomous organisations. In CM, interviewees also found the question of 'policy' problematic. This was because a specific HIV/AIDS youth policy has not existed. There appears to be little or no awareness or engagement among the civil societal respondents of the Thai Government's 2007 HIV/AIDS strategy for young people or the declaratory context provided by global society. Official agency respondents in CM, however, argued that public health policy is adapted from the central government's Public Health Ministry and that: "All in all, our direction has always been in harmony with that of the country"[33]. Similarly, in China, there was a perception among officials and CBOs/NGOs that: "In Kunming, there is no effective strategy for health education including AIDS prevention/education. … There is no specific policy developed specifically for youth'[4]. For some, this is unproblematic. As one senior Kunming Government official argued: 'Policy is not necessary. I feel having policy specifically for youth HIV work is too advanced. But guidelines for practice are important and more realistic"[4]. A few of the interviewees in Kunming

believe that if interventions do not start now, then youth will be a new MARP group in China. Most of those interviewed shared the view that, as far as they are aware of policy, it is vague. Most interviewees do not think there is a specific HIV/AIDS policy for youth. Some were aware of the existence of a Youth Council of Thailand, but were sceptical about its utility with regard to HIV/AIDS. Similarly, in Yunnan, it was argued by a number of interviewees that: "The sustaining challenge is the lack of a longer-term and more effective strategic plan". Clearly, recent moves by the Governments of Thailand and China to devolve greater responsibility to communities and also give additional emphasis to the challenges of young people have not yet had an impact upon the local communities they are intended to reach. In Yunnan, information dissemination is restricted as: "There is also fear to understand the real situation as well as data"[A].

The overwhelming weight of testimony across the whole survey is a consensus on the need to overcome perceived problems of governance through more 'integrated' or "holistic" approaches to policy-making[16]. This is problem is characterised by one Thai respondent as an "irregularity of policy connection"[A]. For some interviewees in CM, KM and Ri, government and civil society work well on HIV/AIDS issues. In Yunnan for example, a senior official at the Ruili AIDS Office in the Ruili Bureau of Health stated that:

> "Collaboration between GO [*sic* governmental organisations] and NGO is very close. There is no clear cutting line between the two. We always invite NGOs and they are treated as GOs. Sadly, we don't have financial support for NGOs.

Comment [G M14]: Response to suggested revision # 2. Indented long quotation

> But they are seen as highly important in local AIDS work. NGOs are included in the government system. I shall expect that we can improve our financial distribution so that NGOs can also be supported financially. All organisations, regardless of their nature, should be part of the work and investment system. There may be conflicts in timing and expectations between NGOs and GOs, but only very minor."[7]

For the majority, of respondents in CM however, official agencies do not gain high marks and are accused, indicatively, of a "neglect of the quality of life of people."[21] In CM, there is a perception among some CSOs of a poor attitude among community leaders on HIV as it is not seen as a legitimate problem and the quality of official work is regarded as low. There is frustration evident within the civil societal sector that policy-makers are disconnected from the practical realities of working with PLWHA and the needs of the latter. Here, testimony from CM noted critically a blanket ban on homosexuals donating blood—something regarded as discriminatory and ignorant of the nature of HIV/AIDS. The Thai "political mess leaves everything in a mess."[21]

In KM and Ri, the issues of governance and policy are also regarded as significant factors. The policies introduced by the central government in Beijing as are the respective provincial and municipal authorities. Again, civil society's practical experience of government is variable. Awareness of specific policies focusing upon youth, sex education and HIV/AIDS is limited, with a number of interviewees arguing that there are no policies specifically addressing young people. Administrative

agencies were problematic insofar as officials were seen to be at a distance from the daily realities of PLWHA and there is a high turnover of officials and a lack of institutional memory that can cause difficulties (for example, one NGO project was stopped for 3 months when a newly appointed official disagreed with and overturned the approach of the previous incumbent in the post).

Concerns regarding policy include administrative changes that appear to be excluding NGOs that previously had been part of the policy-deliberation process in Yunnan:

> "Ideally, the newly formed Yunnan Provincial AIDS Bureau could inform all relevant NGOs with the changes in policy. Previously, we were invited by the HIV/AIDS department in the Yunnan Bureau of Health to meet them and be informed about the latest changes in policy. After the department was restructured to establish the AIDS Bureau, we were no more invited. The very good previous system didn't continue."[10]

Comment [G M15]: Response to suggested revision # 2. Indented long quotation

The political culture of China has changed significantly during the Reform era. With respect to HIV/AIDS, the change has been more recent. As one respondent noted:

> "In the Fall of 2003, I started to understand the AIDS situation in China. At that time, we asked for objective data which was not available from the Government. Things have changed drastically from then to now. Information is still controlled but the level of openness is hugely changed. I don't see any

other country experiencing such a huge policy change. We've seen huge changes in China"[3].

However, a predominant view across the interview survey in Yunnan was that it was the nature of the decision-making structure itself that could be strengthened: "Government tends to choose to do the simplest things. The governmental system is very vertical. Even though people always talk about multi-sectoral approach, but nobody is doing that. This is due to the structure of the government. We start to see collaborations across different sectors but locally this has not been realised"[A]. This point was reinforced by the view of another respondent who noted that the government "is still not open enough. … Internally, the policy is tight. Most people still think AIDS is far away from them, even though Yunnan never recognises itself as high prevalence"[10] This issue of HIV/AIDS and youth governance is tied up with the character of Chinese political culture and the evolving status and role of a 'semi-civil society' wherein the government recognises, authorises, and legitimates non-governmental organisations through registration. Registration provides legal and other protections. Non-registration, therefore, can leave organisations with financial and organisational problems and, according to one interview testimony, even harassment – for example of gay men seeking to form a self-support group[3]. Mostly, however, it is basic administrative limitations and frustrations that are experienced. One respondent noted a problem of gaining Government legal registration as it took his NGO six years from its establishment to gain registration and legal status creating funding problems and constraints in scaling-up services. This is regarded as an issue of Government departments trusting NGOs and,

following registration, the situation improves. According to one interviewee, “Their attitude has changed”[1].

It was noted in the introduction to this paper that a specific interest of the study was to see to what extent global expressions of concern about MARP and young people translate into local community experiences. We have seen that awareness-raising and treatment objectives are evident in the sites under investigation and that challenges such as stigmatisation identified in the global discourse are also present. However, it is important to recognise that this process is not be viewed as a one-way street. The extent to which community voices flow upwards to national and global domains of HIV/AIDS governance must be considered. In the case of CM, KM and R, there is a consultative role for CBOs and NGOs in district, provincial and national policy planning processes. Yet, it is also clear that this role is not fully inclusive and it is not clear from survey evidence the extent to which such participation influences policy outcomes.

To compare this with other sites, the Economic Commission for Africa recently concluded that, in Sub-Saharan Africa: ‘Development-oriented responses to HIV/AIDS are occurring on a small and very local scale. They are seen in some community and NGO activities. However, the models of effectiveness and sustainability and local resource mobilisation that those activities provide have yet to find their way into national or international HIV/AIDS or national development policies and strategies’ (2009: 23)

Comment [G M16]: Response to suggested revision # 9

Towards more effective responses

The principal issues arising from the survey results from both Thailand and China include: (i) questions of definition and hence instrumental focus—just who are the 'young people' we are concerned about?; (ii) policy planning (poor coordination between government policy agencies and CSOs); (iii) implementation difficulties (financial and human resource limitations, absence of practical guidance, variable monitoring of programme effectiveness); (iv) the 'top-down' approach to policy making rather than 'bottom-up'; (v) critically, continuing ambiguity over the participation and role of young people in the formulation and implementation of policy by some health and educational agencies.

Resonating with the wider definitional debate noted above, in both interview cohorts, there was a community issue of how we define youth? Are they children and adolescents? Are they a group of certain ages? It is a group of population without a clear definition? It was argued that policy and practice need to take account of the fact that there are different age groups within young people[23]. This definitional issue has practical implications in terms of policy focus, allocation of scarce resources for specified target age groups, and for the effectiveness of operational programmes. For example, interviews indicated that the effectiveness of school-based sexual health, HIV/AIDS, problem-solving and social skills development programmes required different approaches from those of non-school youth. There was an additional factor identified here, a problem of sustaining youth leadership after school-leaving with many peer-group volunteers not continuing their role into

the wider community[6]. The development of post-school, transitional peer-to-peer mentoring networks and participatory roles in post-school initiatives may provide an opportunity for sustained engagement.

In Chiang Mai interviewees felt that there are many agencies and organisations involved in addressing HIV/AIDS challenges. The problem is not necessarily one of effort or commitment, although this was questioned by two NGOs in CM, but of administrative capacity and of effective coordination. For example, database inadaquacies between departments were singled-out as lacking consistency, unreliable and out-of-date. This was reinforced by a perceived unwillingness on behalf of official agencies to share knowledge or information between themselves or with civil society. A strengthening of database collection, evaluation and dissemination capacity is a pivotal requirement necessitating financial and skills capacity-development from central government and donor community. However, technical upgrading is only likely to be effective if accompanied by changes in organisational cultures. Here the cross-fertilisation of 'better practices' between administrative organisations through international dialogue and work placement exchanges may offer a way forward.

There is a clear need for more effective monitoring of programmes. For the interviewee from the Christian AIDS Ministry in CM, Bhutan's measuring of increased "happiness" rather than economic growth is attractive[28]. In the wider Chiang Mai survey, however, effectiveness appears to be largely qualitatively reflective and mostly based upon impressionistic feedback about behavioural change from

volunteers involved in the programmes. In Yunnan, it was characterised as "highly quantitative, for example, raising the awareness ratio on HIV/AIDS among young people. It is not linked to behavioural change, which is a much more important indicator"[12] Li Xinran from Yunnan Agriculture University's Drug Abuse and HIV/AIDS Office defines effectiveness as having three levels: "knowledge, attitude, and behaviour"[11]. In these communities at least, the consensus is that quantitative targets, *per se*, are a necessary but insufficient means of measuring response effectiveness.

Thailand's Upper North and China's Yunnan Province have long histories of engaging with the challenges of HIV/AIDS. The survey testimony as a whole indicates that there is a genuine sense of achievement in increasing the flow of information (for example through peer-to-peer leadership and monitoring initiatives) and raising awareness in the respective communities and that, for a significant period, infection rates were reduced. However, this feeling is offset by serious reservations about the effectiveness of current initiatives in changing behaviour—a concern reinforced by evidence of increasing prevalence rates.

Here the perceived need to be addressed is for (a) groups to be brought together and involved in the early days of planning and (b) for young people to be actively involved at the community level—to bring them into the processes of consultation, policy formulation and programme implementation. Such involvement also counters some reservations that policy is weighted too heavily in terms of 'top down' approaches and insufficiently 'bottom up'. According to one interviewee in CM:

> "The government has set up the policies without any practical practice on how to achieve the goals. But now, as we have Thailand Youth Network on AIDS, it has become clearer, even though we are not so sure if it will really work as planned. Policies still come from the upper level with still no clear picture of whether teenagers should participate or not. We have to admit that we have already had policies with no practical success. … Policies come from grown-ups. They will always think of a teenager as a small child"[35].

Again, the central feature here is empowerment, with engagement and life-skills development (particularly analytical skills, critical skills that facilitate questioning of established practices and more sensitively perhaps also socio-cultural values) being held to be central to facilitating individual human security. These focus both on the quality of life and on the psychology of those infected, in other words as one Chiang Mai interviewee termed it, a greater emphasis upon the 'social determinism' of the disease is needed. Yet, in this process of inculcating life skills and sex education in the school context, difficulties of human insecurity are being experienced as a consequence of both policy and culture. Whilst Ministry of Health HIV/AIDS strategies embrace such school based curriculum initiatives, there is a view that the Ministry of Education is more 'defensive' in its prevention policy[23]. To an extent, this is reflective of parental sensitivities in traditional cultural values and socialisation expectations grounded in the taboo of openly discussing sex, enduring patriarchy, and life trajectories of study-marriage-children-grandparents. Moreover, generalised campaigns were seen as being constrained by the sheer length of time of HIV/AIDS in

Thailand and Chiang Mai with campaigns 'running out of steam and impact' as public fatigue set-in. There is no quick-fix for this. The community-driven peer-to-peer outreach programmes require additional financial support to engage with families in urban, and especially rural communities.

In addition, the claims of success in Thailand in fighting the disease have led to a drying up of funds to some CSOs. This is a key problem for effectively addressing HIV/AIDS in local communities in Thailand and China. Almost all respondent CSOs identified a growing shortage of funds in recent years. This reflects a view among some national donors that the HIV/AIDS problem had been 'solved' (especially in Thailand) and a perspective among some international donors that both countries are now middle-income economies and have sufficient domestic financial resources to carry on the fight against the disease. This problem is exacerbated by the global financial crisis (WHO, 2009). It is also reminiscent of a reduction in funding during the Asian financial crisis of 1997. Nonetheless, it is clear that International NGOs and foreign government agencies play a major role in CM, KM and Ri. Respondents noted that agencies had been instrumental in providing funding and expertise. However, there was also concern at an over-dependency upon international donors (some local NGOs being 80-90% dependent for funding), reservations about grant conditionality; and the ending of programmes once international donor funding had ceased and moved on to other countries.

In KM and Ri, a sense of having made some progress with regard to HIV/AIDS awareness but that there remained substantial challenges resonated with that of

CM. In terms of policy process, however, the character of the decision-making structure itself is a factor: In China: “The governmental system is very vertical. Even though people always talk about a multi-sectoral approach, nobody is doing that. This is due to the structure of the government. We are starting to see collaborations across different sectors but locally this has not been realised”[2] Similarly, whilst “HIV-related work” takes place in all schools in Ruili (including primary schools), for example, there is still little impact upon young people and children. According to a leading disease control specialist interviewed in Ruili:

> “I have personally advocated for more attention on youth for HIV/AIDS work in various government meetings. But the attention is still very low. Apart from a few NGOs, there is rarely any specific work on youth and children from government. This is related not only to shortages in funding capacity but also to a lack of intervention measures”[9]

Cultural factors also impact upon effectiveness in KM and Ri: ‘’attitude is the long-term sustaining barrier, including that of parents. They feel it is “unclean” to talk about sex and HIV/AIDS to their children as they think the “dirty” AIDS-related behaviours are irrelevant to their children. Most of the parents relate AIDS to drug use and sex work. They don’t want their children to be seen or treated as “MARP”’[4]. In Yunnan, cross-border marriages and differing cultural practices also play a significant part such as earlier starts to sexual relationships and attitudes towards multiple partners. In Yunnan, ethnic cultural diversity means “sex is expressed differently by our youths.” “Language and way of talking” as well as

different moral and sexual attitudes in delivering information and training has to be nuanced as Mandarin, whilst appropriate to central China, can elicit slower responses in the diversity of Yunnan's communities. Thus, 'rural regions are different from urban areas' insofar as the effective delivery of training and HIV/AIDS information are concerned [5]. Poverty, a lower educational level, and a lack of further education opportunities to continue to senior high school – for example, only 300 of 1800 junior high school graduates will continue on to high school in Ruili due to a shortage of places [12]—all work to the detriment of rural communities. The range of mutually-constitutive barriers to health security therefore requires the development of genuinely holistic policy and practice in communities. It is recommended that this is best fostered through stronger 'joined-up' organisational initiatives partnering local CSOs and the donor community in a more integrated and coordinated response culture.

Conclusions

The findings from this study cannot provide a complete picture of how far the efforts of global society translate into community experiences. However, they do shed empirically-based light on a number of key aspects of the continuing challenges of HIV/AIDS as they are experienced in communities by young people living with HIV/AIDS and by community practitioners. The findings underline the conceptualisation of Human Security as one wherein security is multifaceted and mutually constitutive across economic, social, cultural, and political domains. The

findings illustrate with empirical evidence the continuing insecurities and obstacles to self-realisation being experienced by individual and community shared by provincial municipal societies in Thailand and China. They highlight common factors to be addressed in responding effectively to HIV/AIDS such as the role played by inter-generational cultural norms and the complex processes of change generated through globalisation with local impact on the behavioural attitudes of young people towards accepted norms. The objective and aims of the research were underwritten by the idea of support for capacity development. This is grounded in a people-centred approach whereby barriers to the fulfilment of human freedom by young people such as continuing insecurities of stigma and self-stigmatisation, social exclusion, and inequalities of opportunity are targeted and overcome through holistic, inclusive, and 'bottom-up' participatory structures and processes focused on young people. There are significant international and local community efforts to try and meet the challenges of HIV/AIDS faced by young people in both Chiang Mai and Yunnan Province including significant empowerment initiatives driven by young people in these communities. It is important when explaining HIV/AIDS stigmatisation and discrimination not to underestimate personal and community resilience. As Green has demonstrated, people with long-term conditions refuse to be defined by their condition and they are providing an increasingly powerful voice (2009).

But, in responding to Piot's call for a closer understanding of the effectiveness of the myriad of policies and programmes for PLWHA and also noting Harman and Lisk's argument that participation and accountability must be made to count in the global

governance of HIV/AIDS (2009), there are significant obstacles that require urgent policy responses. This is highly salient, not least in terms of improving the awareness and understanding of global society's policies and programmes at the community level.

This study is also concerned with policy implications. The saliency of this was evident in the comment from Ruili AIDS Office that: "It is interesting research as I don't know of any other youth/AIDS projects linked to policy. I would like to see the outcome translated into some kind of pilot programmes, in which Ruili could also participate"[7]. In terms of policy, then, there is a need for enhanced quality of data and for greater access to reliable data at the provincial and municipal tiers of government. There is a need for policy-making processes to allow for greater 'bottom-up' engagement and civil societal involvement, particularly with respect to participation of young people. This is an issue of political and social cultures in transition—of extending adult and government trust and acceptance to CBOs, NGOs and to young people: 'When working with youth, adults should not regard them as trouble makers. They have to believe that youth are the way out of the problem'[22].

Comment [G M17]: Response to suggested revision # 3 on policy implications.

From this requirement, existing NGO interventions designed to facilitate communications and analytical skills[29] and to encourage further the shift in young people from a "passively recipient group" to be a "self-motivated group"[5] should be given encouragement. For instance, in Yunnan, this would also include facilitating the existing first signs of change in the organisational culture of the Youth Leagues

towards a "non-top-down management scheme"[1][10] for school HIV/AIDS volunteer groups where recognised and also extending such recognition. Policy responses also have to look again at the funding provision in the light of reductions in international donor assistance. In addition, we have seen that more robust policies are needed that tackle discrimination and stigma effectively and actively work to empower young people living with HIV. This means working closely with the "gatekeepers" of a site (such as school heads; Youth Leagues) to persuade them to lend their active support[5]. It also requires more "creativity" in working out "how to translate well-intended policy into benefits for target groups"[5]. Here, given a paucity of current involvement in supporting youth programmes[7], a much stronger role for indigenous and multinational business is necessary.

Whilst bearing in mind the point raised across the survey cohort that potential transferable ('better') practices "should be context-specific in different social, cultural and economic settings"[[1][2][5] and caution over "a tendency to think that foreign things are better"[8], this research demonstrates that there are opportunities for additional South-South dialogue and learning (SSL) for inter-community capacity development. This is evident in the common challenges faced and to identify the continuing challenges and the many community-led support programmes in Chiang Mai, Kunming and Ruili such as "volunteer self-management", peer-to-peer support networks, life-skills training[1]. This can build on initiatives such as the "South-to-South Exchange Programme between Thailand and Africa" of the Christian AIDS Ministry[28].

Increasing knowledge and awareness among young people and their communities remains a vital requirement. However, in the final analysis, this study reinforces the point that the single most important challenge is to change behaviour among young people to reduce risk: "how to make knowledge become behavioural change"[7]. This, at a time when socio-economic transitions, new technologies and globalisation are making it "now more difficult to grasp their expectations"[5][7]. Despite the advances that have been achieved, the empirical evidence indicates that there is still a long way to go in meeting this challenge in local communities in East and Southeast Asia and beyond.

Notes

1. HIV stands for 'human immunodeficiency virus'. AIDS refers to 'acquired immunodeficiency syndrome' and is 'a surveillance definition based on signs, symptoms, infections, and cancers associated with the deficiency of the immune system that stems from infection with HIV.' (UNAIDS).

2. The link between poverty and HIV?AIDS was, however, controversial in South Africa. This was particularly acute with regard to claims of 'denialism' and a rejection of the 'scientific consensus' raised against then President Mbeki who chose to advocate a minority view that HIV did not cause AIDS but that it was attributable instead to poverty as the primary factor. The U.N.'s Special Envoy, Stephen Lewis, criticised the Mbeki-led South African Government as "obtuse and negligent" at the

Comment [G M18]: Response to suggested revision # 13

International AIDS Conference in Toronto (Mbeki, 2000; Barnett and Whiteside, 2002; Tladi, 2006).

Appendix: Interviewee citations

Comment [G M19]: Response to suggested revision: # 13

China (N.B. organisational titles cited only; interviews conducted under anonymity, December 2008-September 2009):

[1] AIDS Care Home;
[2] HIV/AIDS Programmes Coordination Office, Bless China International;
[3] International AIDS Alliance Kunming Office;
[4] Kunming Government Family Planning Committee;
[5] Kunming Public Health School,
[6] Public Health School, Kunming Medical College;
[7] Kunming Institute of Health Education;
[8] Ruili AIDS Office, Ruili AIDS Office, Ruili Bureau of Health;
[9] Yunnan Institute of Drug Abuse;
[10] Ruili Municipality CDC;
[11] Youth Health Project, Youth Health Project of Save the Children;
[12] Drug Abuse and HIV/AIDS Office, Yunnan Agriculture University;
[13] Ruili Women and Children's Development Centre;
[14] Yunnan Ruili No.3 Ethnic Minorities Middle School;
[15] Yunnan Homeland Resources College;
[16] Kunming Medical College Hai Yuan School HIV/AIDS Volunteer;
[17] Yunnan Ruili No.3 Ethnic Minorities Middle School;
[18] Kunming HIV/AIDS School Volunteer;
[19] Kunming HIV/AIDS Community Schools Advocacy Organisation;
[20] Yunnan Homeland Resources College, HIV/AIDS Volunteer.

Thailand:

[21] Ms. Jutatip Dechaboon, Country Coordination Officer, HIV/AIDS Action Centre, Health and Development Networks, 4 February 2009;
[22] Mr.Toon, Upper Northern Child and Youth Network, 2 February, 2009;
[23] Miss Pattharawan Thepnamwong, Project Manager of Youth HIV and AIDS Prevention Education Project, Project Hope in Thailand, 14 December, 2009;
[24] Mr. Udom Likitwannawut, Northern Thailand Coordinator, CARE-RAKS Thailand, 16 January, 2009;
[25] Miss Anchalee Jomatan, Programme Development Officer, AIDSNet Foundation, 13 January, 2009;
[26] Mr. Sirasak Chaited, Youth Outreach Staffer, M Plus, 16 February, 2009;
[27] Mr. Ummarin Norchaivong, Academic Health Officer, Division of HIV/AIDS Protection, Sarapee Hospital, 23 December 2008;

[28] Mr. Sanan Wutti, Reverend Director, The Christian AIDS Ministry, Church of Christ in Thailand, 5 February, 2009;
[29] Mrs. Siriluck ungkoonpiriya, Director, Thai Youth Action Programme, 29 January 2009;
[30] Dr. Chawan Hormmalee, Director of Office of Student Development Services, Payap University, 19 February, 2009;
[31] Mrs. Utchara Sriparakit, Staffer, Student Development Division, Chiang Mai University, 3 February, 2009;
[32] Mr. Manoon Gaikharnkaew, Academic Health Officer of CDC 10, Chiang Mai CDC (Region 10), 2 February, 2009;
[33] Dr. Chonrlisa Chariyalertsak, Head of STD/AIDS Prevention and Control Section, Chiang Mai Provincial Public Health Office, 2 February, 2009;
[34] Mr. Tip Piroon, Academic Officer of Educational Service Area 1, Chiang Mai Educational Service Area Office 1, 4 February 2009;
[35] Miss Suchada Suwanthep, Project Coordinator of AIDS Orphans Fund Project North Net, 13 February, 2009.

A. Organisation citation withheld.

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