

Young women sex worker participation in HIV policies and programmes in Thailand

Kristel Modderman

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Abstract

The participation of young women sex workers in Human Immunodeficiency Virus (HIV) policies and programmes is necessary for addressing HIV among this most-at-risk population. The Thai government has recently made a commitment to increase sex workers' participation levels in HIV interventions; this study sets out to explore this issue. Young women constitute a very high proportion of sex workers in Thailand and experience greater vulnerability than older sex workers; it is therefore of great importance that they play a key role in participation.

This study asked: To what extent do young women sex workers in Bangkok, Thailand participate in HIV policies and programmes? Five young women sex workers from Bangkok were interviewed regarding their views and experiences of participation in HIV policies and programmes. Staff from a Civil Society Organisation (CSO), working with young women sex workers took part in a small focus group discussion to gain their insights on this issue.

The findings identified a number of challenges and barriers to participation, with few examples of meaningful participation. The challenges and barriers to participation in HIV policies and programmes in Thailand were related to; fear and trust of the authorities; stigma; the illegal nature of sex work and other aspects of the sex industry; low educational levels and the subordinate position of young women in Thai society. Some examples of sex worker participation today appear to follow the peer education model. These were however found to be under-resourced, lacked organisation and were not based on an empowerment model of participation. Participation by young women sex workers at the CSO level included some input into the national prevention strategy, but was found to be largely tokenistic.

This study displays the alarming situation currently faced in regards to young sex worker participation in HIV policies and programmes. It is however encouraging to note that young women sex workers who participated in the research demonstrated a desire for greater involvement in HIV policies and programmes in a meaningful way. Greater participation may aid in identifying innovative approaches for improving sex worker-targeted HIV policies and programmes, even within this resource constrained environment. It is crucial that sex worker collectives play a

leading role in supporting and advocating for young sex worker participation. Also of great importance is the role of powerful actors such as donors, the Thai government and non-government organisations in supporting the efforts of sex worker collectives.

Table of contents

Attestation of Authorship	9
Acknowledgements	10
Chapter 1: Introduction	11
1.1 Background and rationale	11
1.2 Generating the research question.....	16
1.3 Definition of terms	18
1.4 Contribution to HIV among young women sex workers and public health.....	18
Chapter 2: A review of young women sex workers in Thailand, HIV risk, and participation in HIV policy and programmes	20
2.1 Introduction	20
2.2 Situating young sex workers in Thailand	21
Poverty	21
Education	21
Gender equality	22
2.3 HIV and young women sex workers in Thailand	24
Legislation.....	24
Trafficking	25
Migration.....	25
Stigma and marginalisation.....	26
Violence	27
Drug Use	27
Place of work	28
2.4 Conclusion.....	29

Chapter 3: Participation theories, young women sex workers and HIV policies and programmes.....	30
3.1 Introduction	30
3.2 Thai concepts of community participation in health	32
3.3 Participation theories and frameworks	35
3.4 Community and sex worker participation in HIV policies and programmes	43
3.5 Conclusion.....	47
Chapter 4: Young women sex workers' participation in HIV policy and programmes in Thailand: a study design.....	50
4.1 Developing the research	50
4.2 My role as the researcher.....	52
4.3 Methodology and methods	53
4.4 Data collection.....	55
Participants.....	55
Location of the research.....	56
Preparing for participant recruitment and interviews	57
Conducting semi structured interviews.....	58
Data analysis	59
Ethical considerations	60
4.5 Conclusion.....	61
Chapter 5: Young women sex workers and participation in HIV policy/programmes in Bangkok	63
5.1 Introduction	63
5.2 Importance of participation	63
5.3 Current participation.....	66
Peer education.....	66
Advisory groups.....	68

Anti-stigma programme with local police	69
5.4 Barriers	70
Issues of fear, trust, power and the illegal nature of sex work.....	70
Youth, inexperience and gender roles	74
Issues of voicelessness and wanting a voice	75
5.5 Opportunities for future participation.....	77
5.6 Conclusion.....	78
Chapter 6: Implications of the study of participation of young sex workers in Thai HIV policy and programmes.....	79
6.1 Introduction	79
6.2 Ladder of Citizen Participation	79
Therapy and manipulation	79
Informing	81
Consultation	83
Placation.....	84
Partnership	86
Delegated power	87
Citizen control.....	88
6.3 Conclusion.....	91
6.4 Recommendations	92
References	93
Appendices	105

List of Figures

Figure 1. Ladder of Participation.....	36
Figure 2. Pentagram Model of Community Participation.....	39

List of Tables

Table 1. Young women sex worker participants.....	56
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Attestation of Authorship

“I hereby declare that this submission is my own work and that, to the best of my knowledge and belief, it contains no material previously published or written by another person (except where explicitly defined in the acknowledgements), nor material which to a substantial extent has been submitted for the award of any other degree or diploma of a university or other institution of higher learning.”

Signature.....

Date.....

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Chapter 1: Introduction

1.1 Background and rationale

Globally, the Human Immunodeficiency Virus (HIV) remains a significant public health issue. In 2012, it was estimated 35.3 million people were living with HIV, which included 2.3 million new infections (Joint United Nations Programme on HIV/AIDS [UNAIDS], 2013). While Thailand has experienced notable success in reducing HIV prevalence (United Nations Development Programme [UNDP], 2004), UNAIDS still classifies Thailand as a country requiring intensified efforts to improve access to HIV treatment. This classification is in response to the 90% of people living in the country with HIV (PLHIV) who are known to have an unmet need (UNAIDS, 2013). Thailand's no nonsense, pragmatic response to the Acquired Immune Deficiency Syndrome (AIDS) epidemic has been one of the most successful efforts globally in preventing new infections (UNDP, 2004). Thailand is however an example of a country where success can be relative. Unless past efforts are sustained, the remarkable achievements made in controlling the epidemic could be threatened, placing Thailand at risk of facing a resurgence of infection in future generations. As one of Thailand's most at risk groups for HIV infection, young women sex workers are a particularly important target for public health research.

Thailand's response to the HIV epidemic

Thailand was one of the first countries to experience the HIV/AIDS epidemic, with its first case of HIV reported in 1984 (Liamputtong, Haritavorn, & Kiatying-Angsulee, 2009). It was the rapid growth of HIV infections amongst Injecting Drug User (IDU) populations in 1988 that encouraged the development of a national sentinel surveillance system in 1989 (UNAIDS, 2000). The Thai government committed significant political and financial resourcing in the early 1990s and the National AIDS and Prevention and Alleviation Committee was developed to oversee a comprehensive strategy. Efforts towards HIV/AIDS in the 1990s resulted in a decrease in new infections from 143,000 in 1991 to 19,000 in 2003 (UNDP, 2004). This rapid decline in new infections was largely attributed to the implementation of the 100 percent condom programme, piloted in 1989 and implemented nationally in 1991. The programme was centred on encouraging sex

workers to adopt a “no condom – no sex” approach in all sex establishments (Rojanapithayakorn, 2006).

As part of the aggressive and comprehensive strategy to address the HIV epidemic, voluntary counselling and testing (VCT) services in Thailand commenced in 1992. VCT is a client initiated service that allows individuals to learn their HIV status in conjunction with pre and post-test counselling (World Health Organization [WHO], 2002) and is aimed at helping participants to better cope with their HIV status. A meta-analysis conducted by Weinhardt, Carey, Johnson and Bickman (1999) on the value of VCT as a behaviour change intervention, found that HIV positive individuals who used VCT reduced their risk behaviours and had safe sex more frequently. The majority of VCT services were established in Thailand in 1992. These were predominantly government directed and provided through anonymous VCT clinics in all government hospitals, STD clinics and some health centres at a fee to the participant of US\$5-\$6 for the complete sequence of services (Kawichai, 1992). This fee was in line with VCT services available in Nairobi in 1999 who also charged participants US\$6 (Forsythe, Arthur, Ngatia, Mutemi, Odhiambo & Gilks, 2002) but more expensive than many VCT services available globally in later periods. In 2003, the cost of VCT to participants was US\$0.95 in Tanzania (Thielman et al., 2006) and US\$1 in Cambodia (UNICEF East Asia and Pacific Regional Office, 2007).

The issue of cost is important. Thielman et al. (2006) demonstrated that a period of free VCT significantly increases the number of clients undergoing VCT and enhances cost effectiveness when integrated within an existing AIDS service framework. Kawichai's (2004) study on VCT services, implemented in rural Chiang Mai Thailand, noted that the most frequently cited motivation by the 427 participants for seeking VCT was that the services were free of charge. When barriers to VCT uptake such as cost were removed by providing free VCT services, rural residents responded by participating in these services in larger numbers. Targeting groups with less access to health care, with effective strategies such as affordable VCT is a critical approach in preventing the resurfacing of the HIV epidemic.

In 1996, Thailand reached a peak in HIV funding (UNAIDS, 2004). However, the economic crisis in Thailand during 1997 resulted in the government budget being scaled back by 18.5% which placed considerable constraints on public

resources and HIV/AIDS programmes (UNAIDS, 1999). This budget stress resulted in an increase in new infections and maintenance of high HIV prevalence among high risk groups such as sex workers, IDUs and men who have sex with men. These groups continue to be the most affected by HIV globally (UNAIDS, 2012). The reduction of disposable income in this period may have limited access to HIV treatment and lead more young people into sex work due to lack of job prospects (UNAIDS, 1999). In 2006, a guideline was released by the US Centers for Disease Control (CDC) recommending routine HIV testing in all public and private healthcare settings in order to reduce the number of infected people unaware of their HIV status and lessen the number of late diagnoses (CDC, 2006).

Despite efforts to prevent the spread of HIV, between 2005 and 2008 the number of non-brothel sex workers who were HIV positive doubled. HIV infection rates were also five times higher for non-brothel sex workers when compared to brothel workers (National AIDS Prevention and Alleviation Committee, 2010). For the context of this study, non-brothel sex work refers to sex work that is negotiated at venues such as nightclubs and bars. Brothel based sex work refers to that which is paid for and occurs on premises organised around sex as a business, for instance brothels or massage parlours (Kerrigan et al., 2013). Although sex workers were the most-at-risk for contracting HIV in Thailand in 2009, only a small proportion of Government funding was allocated to the prevention of HIV among this group. In 2009, the budget for HIV/AIDS prevention among sex workers was only four million baht (US\$116,000 and 0.4% of total HIV/AIDS prevention expenditure); a decrease from the previous year of 10 million baht (US\$303,000). Total expenditure on HIV/AIDS also decreased, from 1500 million baht (US\$45 million) in 2008 to 987 million baht (US\$29 million) in 2009 (National AIDS Prevention and Alleviation Committee, 2010). This data came out of the 2010 *UNGASS Country Progress Report* which reports on progress between 2008 and 2009. Two sex worker collectives, 'Empower' and 'Swing' were noted in the 2010 report as being part of the 'National Technical Working Group on Monitoring and Evaluation for HIV Prevention among Sex Workers'; thus indicating the participation of sex worker collectives in HIV prevention. However details of the nature of this participation are lacking.

Between 2010-2011, HIV prevention measures in Thailand continued with support from the Global Fund, an international financing agency which is the largest funder of HIV/AIDs initiatives. The Global Fund receives its funds through a mix of public and private sector donations; it should however be noted that the global financial crisis has seen a decrease in the amount donated in recent times. As countries like Thailand move to transitional economies, their ability to secure funding from external sources is likely to decline putting extra pressure on domestic sources. It is therefore of no surprise that HIV prevention is now predominantly carried out by not-for-profit organisations with minimal financial support and resourcing from government (National AIDS Prevention and Alleviation Committee, 2012). In 2010 and 2011, the political sector pushed for implementation of the *National Aids Plan* which would result in an increase in funding targeted at prevention. However in 2012, due to a lack of national leadership, the substantial financial allocations to prevention had not been made (UNAIDS, 2012). Between 2012 and 2013, the Global Fund provided the majority of the prevention budget for most-at-risk-groups such as sex workers (National AIDS Committee, 2014).

Young women sex workers and HIV in Thailand

Due to the nature of their work, the likelihood of a sex worker contracting HIV is much higher than the general population, and this is compounded by a number of risk factors such as violence, stigma, drug use and place of work (UNAIDS, 2012). Globally, HIV rates have been found to be 13.5 times higher among sex workers when compared to the general adult population (The World Bank, 2013). Furthermore, the WHO (2012) estimated that from data reported between 2007 and 2011, global HIV prevalence among sex workers is at a distressing 11.8%. In Thailand, estimates of the number of sex workers varies greatly depending on the source of information and factors influencing the quality of information. Shame, trafficking and risky places of work continue to be underlying barriers to accurate estimations. Article 3, paragraph (a) of the Protocol to Prevent, Suppress and Punish Trafficking in Persons defines human trafficking as the “recruitment, transportation, transfer, harbouring or receipt of persons, by means of the threat or use of force or other forms of coercion, of abduction, of fraud, of deception, of the abuse of power or of a position of vulnerability or of the giving or receiving of payments or benefits to achieve the consent of a person having control

over another person, for the purpose of exploitation” (United Nations Office on Drugs and Crime, 2000, p. 42). A large proportion of sex workers recorded in studies are under 18 years of age. In a study among female sex workers in Thailand, 25% were less than 18 years of age, and of those who were trafficked into sex work, 84% were less than 18 years of age (Decker, 2010). A recent study among 130 adolescent female sex workers, across four geographical regions in Thailand, found that participants on average commenced work in the sex industry at the age of 13.3 years old (Moraros, Buckingham, Bird, Prapasiri, & Graboski-Bauer, 2012).

In recent years, a shift in the sex industry has seen higher numbers of non-brothel sex workers (Manopaiboon et al., 2013). The high numbers of sex workers who work in these other venues is particularly problematic for addressing HIV. Invariably these sites have less internal regulation than brothels and sex workers are more vulnerable to sexual violence, have reduced capacity to negotiate condoms, and less access to condoms, outreach and health services. These factors may explain the higher rates of HIV present amongst this group (Manopaiboon et al., 2013). Young sex workers in Thailand are at greater risk of HIV due to their youth, their exposure to the risks of trafficking, exploitation and sexual violence; they are also more vulnerable and voiceless than older sex workers. These factors combined reduce their ability to negotiate for condom use and access services (Silverman, 2011). The particular vulnerability and proliferation of this group justifies the focus of this study on young women sex workers. Those who are at risk also lack the opportunity to take steps to prevent HIV, and combined with the disadvantage of female physiology in relation to HIV infection, experience higher prevalence rates (Decker, 2010). Young women sex workers have been found to have little access to condoms due to financial constraints, which is why a number of them enter into sex work in the first instance (Moraros et al., 2012).

Young women sex workers and participation

There is wide-spread agreement that sex worker participation is a key theme in addressing HIV among this most-at-risk group (Chakravarthy, Joseph, Pelto, & Kovvali, 2012; Galavotti, Wheeler, Kuhlmann, Saggurti, Narayanan, Kiran, & Dallabetta, 2012; Kerrigan et al., 2013). The WHO (2012) stated “the most successful interventions with sex workers have combined multiple components – implemented with strong community involvement and backed by supportive policies – to

maximize positive outcomes” (p. 37). The *UNAIDS Guidance Note on HIV and Sex Work* stated that HIV-related services “should be designed with the full participation of the affected community” (UNAIDS, 2009, p. 11). To date there are both international and Thai examples of sex worker participation in HIV policies and programmes. The Sonagachi Project based in Kolkata, India, focused on four main domains for sex worker participation which included (1) participating in accessing project services; (2) participating in providing project services; (3) participating in shaping project workers’ activity; (4) participating in defining project goals (Cornish, 2006). Adapted from the Sonagachi Project, the Swagati Project in Andhra Pradesh, India developed community-based organisations of sex workers. These organisations were responsible for delivering peer-led outreach, information campaigns, institution building through community committees and capacity building for organisational development (Chakravarthy, Joseph, Pelto, & Kovvali, 2012).

In the case of Thailand, there are various examples of sex worker participation in HIV policies and programmes. One example is the 100% condom programme (piloted in 1989), which involved participating brothels promoting and adhering to a “no condom, no sex” policy, HIV and safe sex education and the distribution of free condoms (UNAIDS, 2000). Another example of sex worker participation in Thailand is one of peer education, a strategy used globally in HIV prevention (Cornish & Campbell, 2009). Two studies note that peer education has been implemented with some success in Thailand since the mid-1990s (Van Griensven, Limanonda, Ngaokeow, Isarankura Na Ayuthaya, & Poshyachinda, 1998; Visrutaratna, Lindan, Sirhorachai, & Mandel, 1995). In a study by Van Griensven et al. (1998) it was demonstrated that peer education resulted in a pronounced increase in HIV related knowledge and perceived vulnerability when compared to a control group. Within this study the intervention group received educational training from peer educators on the prevention of the sexual transmission of HIV.

1.2 Generating the research question

My decision to conduct research within this area was influenced by my unique research experiences and ethnicity. In 2010 I conducted a research assignment on needle exchange programmes in Nepal. It was then that I learnt of the difficulties that sex workers face, especially those with HIV, in receiving and gaining access to a range of health services and programmes. Those sex workers who were

most at risk of HIV were young women. Being a young woman, I was particularly interested in research that focused on issues for young women sex workers. I was keen to know why HIV rates in Thailand were still so high and why few young women were accessing health-related services, even though Thailand is a middle-income country. Furthermore, due to my South-East Asian heritage, I was drawn to conduct my research in a South-East Asian country.

In 2011, I conducted a review of research in Thailand on sex workers which led me to understand that young women sex workers in Thailand were at increased risk of HIV. There was however little evidence to show that they were at the centre of services and programmes targeted at sex workers. This knowledge gap was the main inspiration for this study. I knew that in order to carry out my research, I would need strong links and support from those working in this area in Thailand. After conducting the review in 2011, I participated in a study tour in North-East Thailand (where HIV rates are among the highest) later that year.

The aim of this trip was to try to establish links with researchers and practitioners who worked with sex workers infected with HIV. However, those who I did meet in the health sector had only worked with families in the area of treatment and care and had no experience in working with sex workers, nor did they know of anyone working in this area. When I returned to New Zealand I advised my supervisor of my findings. She then introduced me to a colleague of hers who was working with the Institute for Population and Social Research (IPSR) at Mahidol University in Bangkok. My third supervisor and the IPSR hosted me during my data collection period and introduced me to a CSO, known as Service Users in Group (SWING) who assisted with participant recruitment. SWING are based in the major tourist destinations of Thailand: Bangkok, Pattaya and Samui, and provide education, health education, outreach activities and other projects that are aimed at empowering all sex workers. The organisation also works at the local and national level, advocating for the equal rights of sex workers. Currently 80% of SWING's staff have, at some point in time, previously worked as sex workers themselves (Service Workers in Group, 2014).

The above experiences and opportunities led me to develop the following research question: To what extent do young women sex workers (YWSWs) in Thailand participate in HIV policies and programmes?

To explore this question I asked the following sub-questions:

- Do YWSWs think that participation in HIV policies and programmes is important and if so why?
- What is the extent of current participation of YWSWs in HIV policies and programmes?
- What are the barriers and future opportunities for YWSW participation?

1.3 Definition of terms

The following are key terms, as guided by the research question: young women sex workers (from here on I will use the acronym YWSW); participation; HIV policies and programmes; Thailand. For the purpose of this study, the term ‘young women sex worker’ or YWSW refers to those aged between 20 and 24 years of age. However as Silverman (2011) noted in his study, which looks at age at entry into sex work, there are many sex workers who are younger than 18 years of age. I used this age band as 18 is the universal age for consent. Researching sex workers who are less than 18 years of age increases the risk of being exposed to participants who are trafficked and has ethical implications. Those under 18 years may also not understand the potential risks of being involved in research related to their involvement in employment of an illegal nature.

1.4 Contribution to HIV among young women sex workers and public health

HIV is a global public health priority and sex workers (especially young women) are among the most at risk and affected population. The environment in which sex work takes place continues to be risky and constantly changing. In order to be responsive to this change, governments must realise the importance and urgent need to involve sex workers in addressing HIV. Traditionally, HIV policies and programmes targeted at YWSWs focus on health education, condom use and testing via a top-down approach. This study will contribute to HIV and public health by exploring the nature of YWSW participation in Bangkok, Thailand; and the opportunities and barriers that exist within policies and programmes. Given the limited knowledge base on YWSW participation in the Thai context, this study aims

to contribute to academic debate on strategies for increasing participation within a context that experiences social, cultural, economic and legal challenges. It may also have wider relevance for other South East Asian countries, and for HIV policies and programmes relating to YWSW in transitional economies.

This research was conducted in partnership with Mahidol University's Institute for Population and Social Research (IPSR), and was part of a broader research project to evaluate the National HIV Prevention Program among Most at Risk Populations, Prisoners and Migrant workers (Institute for Population and Social Research [IPSR], 2013). In the IPSR's study, female sex workers (FSW), men-who-have-sex-with-men (MSM) and people who inject drugs (PWID) are referred to as key affected populations (KAP). This current study contributes to IPSR's study as it provides an analysis of one of the research questions that IPSR's study attempted to answer, which was "what is the extent of participatory involvement of KAP in planning and evaluating services"?

This thesis consists of six chapters. In the first chapter, I use the literature to set the scene and introduce the topic and research problem. A review of the literature is further discussed in Chapters two and three. Chapter two provides a critical review of the literature relating to young sex work and HIV risk in the Thai context, and Chapter three discusses participation theories and HIV policies and programmes. In Chapter four, the research methodology and methods, data collection and analysis are discussed. Findings from the interviews are presented and analysed in Chapter five with reference to an analytical framework of the ladder of citizen participation (Arnstein, 1969). Finally, Chapter six summarises the findings and makes recommendations for HIV policy makers.

Chapter 2: A review of young women sex workers in Thailand, HIV risk, and participation in HIV policy and programmes

2.1 Introduction

In addressing HIV, it is suggested that community participation has benefits for the individual, government and the broader community (Kim, Kalibala, Neema, Lukwago, & Weiss, 2012). The individual gains an opportunity to learn about and shape more meaningful responses to HIV. Through increased knowledge the individual is empowered to participate with greater effect in HIV policy and programme development and take a more active stance in his or her personal life in advocating the importance of participation with peers (Cornish & Campbell, 2009); which may result in greater collective action (Chakravarthy, Joseph, Pelto, & Kovvali, 2012). Policy makers and programme planners are then, as a result, afforded an opportunity to have more meaningful dialogue with communities in respect to exploring the underlying barriers to effective community engagement in HIV programmes. (Gibbs, Campbell, Maimane, & Nair, 2010; Maxwell, Aggleton, & Warwick, 2008). Meaningful involvement of sex workers in HIV services will also aid in breaking down negative community attitudes surrounding sex work (Kuhlmann, Galavotti, Hastings, Narayanan, & Saggurti, 2014), making it easier for sex workers to access much needed services, such as HIV testing. Furthermore, internal benefits such as greater self-esteem and confidence, can be gained; further improving the effort of empowering this most at risk group to participate in HIV policy and programmes (Wallerstein, 1992, 1999).

This chapter critically reviews the literature that situates YSWs and HIV risk; and how these factors relate to Thai HIV policies and programmes. In the forthcoming section, the wider social drivers of sex work, such as poverty, lack of education and gender inequality, are discussed. This is followed by a discussion of the more direct factors that put YSWs at risk of HIV, for instance legislation, trafficking, migration, stigma and marginalisation, violence, HIV knowledge, drug use and place of work.

2.2 Situating young sex workers in Thailand

Youth

Evidence suggests that, in Thailand, many women enter sex work at a young age (Goldenberg et al., 2012; Hemalatha, Hari Kumar, Venkaiah, Srinivasan, & Brahmam, 2011). In 2012, an estimated 40% of the two million female sex workers were under the age of 18 (Moraros, Buckingham, Bird, Prapasiri, & Graboski-Bauer, 2012), and of those trafficked into sex work, 84% were less than 18 years of age (Decker, 2010). Other studies have shown that a significant number of sex workers are younger than 15 years of age (Decker, 2010; Limpakarnjanarat et al., 1999; Silverman et al., 2006). It should be acknowledged that in countries where HIV prevalence is high amongst sex workers, there is also a large youth population (Monasch & Mahy, 2006).

Poverty

Sex work is one of the few options available to young women who lack formal education and who come from a poor family (Swendeman, Basu, Das, Jana, & Rotheram-Borus, 2009). Poverty is a complex and multidimensional concept that extends beyond economic position. In 2011, it was estimated that 13.2% of Thailand's population was below the poverty threshold defined by the World Bank (n.d); meaning those who receive little income are further burdened by their inability to afford an education leading to fewer job prospects, which is a major factor driving young women into sex work.

Education

Nemoto, Iwamoto, Sakata, Perngparn, and Areesantichai (2013), in their study on Thai female sex workers in Bangkok, found that 71.2% of participants (n=205) did not have a secondary level education. This is particularly low compared to the 87.3% of female students enrolled in secondary education programmes in 2012 throughout Thailand (United Nations Educational Scientific and Cultural Organisation [UNESCO], 2014). Additionally, a study based in Chiang-Mai on cervical cancer prevention among sex workers found that only 22.4% had primary school education (Kietpeerakool, Phianmongkhon, Jitvatcharanun, Siriratwatakul, & Srisomboon, 2009), which is distinctly lower when compared to the 94% enrolment rate of females in primary school in Thailand in 2009 (UNESCO, 2014). Education

is a basic human right (UNESCO, 2014). The attainment of a good education has far-reaching benefits and has the ability to remove those who are the most marginalised from society out of poverty (UNESCO, 2014; World Bank, 2006). Barriers to gaining a good education exist, with direct costs such as school fees and transport (National Statistical Office, 2008; Tharmmapornphilas, 2013) and indirect costs including library fees, and fees to sit examinations, disadvantaging poor students. These direct and indirect costs of schooling notably increase the total cost of education, further disenfranchising many poorer children, largely from rural areas who are then forced into leaving school (Tharmmapornphilas, 2013).

Vulnerable groups such as those from rural areas of Thailand and urban migrants show low participation rates in education (UNESCO, 2011). While the 1997 Constitution of Thailand entitles all children up to 12 years of age free education, in rural areas, this has not translated into greater participation in education. Large numbers of rural children work in agriculture and other labour based jobs to contribute financially to their families (UNESCO, 2011). Language further acts as a barrier to education for migrant children; and despite efforts to reach out-of-school migrant youth, these have been small in scope and mostly led by non-governmental organisations (World Bank, 2006).

Children with educated parents tend to achieve higher secondary school participation rates. The educational attainment of adult males and females are both positively associated with children's participation in secondary school. The higher the educational attainment of the adult in a household, the more likely the children in that particular household will participate in school. The effect is even stronger with females (World Bank, 2006). As such, it should be expected that the likelihood of a young woman becoming a sex worker would be greatly reduced if the parents of that young woman are well educated. Consequently, education has been strongly associated with HIV among women and girls in Thailand (Greener & Sarkar, 2010).

Gender equality

The inability for women in Thailand to achieve gender equality is another factor driving young women into sex work. Generally speaking, gender equality refers to the “the equal rights, responsibilities and opportunities of women and men and girls and boys” (United Nations Children's Fund [UNICEF], 2011, p. 2). The United Nations Taskforce on Education and Gender Equality (2005) described

women's equality as being made up of five components: (1) women's self-worth, (2) the right to have and determine choices, (3) the right to have access to opportunities and resources, (4) the right to have power to control their own lives, both within and outside the home and (5) the ability to influence the direction of social change to create a just, social and economic order.

Aspects of gender inequality are still present in Thai society to this day. The practice of 'bunkhun' is held with high regard in Thai culture and is even more common in rural areas. In essence, bunkhun can be described as a kind of filial piety, but also extends to other relationships such as worker-employer (Liamputtong, Yimyam, Parisunyakul, Baosoung, & Sansiriphun, 2004). Generally speaking, this means that if someone does something good for you, you must do so in return. Although it is not expected that the act of kindness is reciprocated in the same fashion, it is expected that the beneficiary find opportunity to express their gratitude in some manner (Liamputtong et al., 2004). As such, it is cultural practice in Thailand for young people to economically support the family, which includes repayment for upbringing and to assist with providing for the younger members of the family.

The consequence for not fulfilling bunkhun to one's parents is called 'knonnerakhun' or 'khonakatanyu'. Thai's believe that this results in misfortune and illness in this life and lives to come (Liamputtong et al., 2004). The cultural pressure to support the family has been previously identified as one of the reasons young women turn to sex work (Kanchanachitra, 1998; Taylor, 2005). The pressure to financially support the family is also evidenced in the proportion of sex workers sending remittance payments home. Nemoto et al. (2013) found that 93% (n=99) of participants working in a bar or night club and 93% (n=60) of participants working in a massage parlour sent money to their family. The same study reported that over 86% of sex workers stated that they would engage in unsafe sex for more money. This demonstrates that the pressure for these young women to repay their bunkhun may also be influencing their risk of contracting HIV. Repaying of their bunkhun may also be a factor in their decision to stop or report sexual violence for fear of losing payment or attracting unwanted attention from the police.

Over the past two decades, there has been some progress in reducing gender inequality within Thailand. This has been achieved in part through legislation to

improve employment and educational opportunities for women (Yukongdi, 2005). It must be said, that Thailand has some way to go before achieving gender equality. Despite education rates among women surpassing those of males, women have not achieved higher earning power than their male counterparts (Nakavachara, 2010). While women make up 50% of the Thai population, they only hold 16% of the seats in parliament (UNDP, 2012). The absence of legislation to enforce child maintenance payments for single parents also contributes to gender inequality and, as noted by Ratinthorn, Meleis, and Sindhu (2009), creates pressure for young women to earn money – potentially impacting employment choices and HIV risk.

2.3 HIV and young women sex workers in Thailand

Data from the National HIV Sentinel Surveillance survey data shows a decline in HIV among women sex workers, with prevalence at 2.8% in 2008, 2.2% in 2010 and 1.8% in 2011 (UNAIDS, 2012). HIV prevalence among indirect sex workers is, however, very difficult to monitor and a low ‘official’ rate is likely inaccurate and may mask HIV prevalence among YSWs, who are at higher risk of infection. A recent study in Bangkok among 707 non-brothel based female sex workers, with a median age of <25 years, found HIV prevalence at 20.2% which is around 10 times higher than that found among brothel based women sex workers and approximately 20 times higher than that of the general population (Manopaiboon, 2013). This great difference indicates the vulnerability of YSWs as a whole, and non-brothel based sex workers in particular, as non-brothel workers are outside formal HIV prevention programmes and may not be receiving the same level of attention as brothel based sex workers. Beyond the wider social factors discussed above, there are other factors relating to HIV risk which are of concern in relation to YSWs.

Legislation

The legal landscape has a direct impact on HIV risk among sex workers. Sex work is illegal in Thailand and is legislated by the Prevention and Suppression of Prostitution Act, B.E. 2539 (1996). The legislation states that sex work is illegal if conducted in a “promiscuous manner”; however the term is not defined within the legislation (HIV and AIDS Data Hub for Asia-Pacific, 2010). The Entertainment Places Act of 1966, while it does not explicitly legalise sex work, allows places of entertainment to offer “special services” (HIV and AIDS Data Hub for Asia-Pacific,

2010). As this legislation does not explicitly state what conduct is punishable, there exists an ambiguity which creates an environment that can be exploited to conduct sex work within a sex industry which openly exploits sex workers. This environment creates fear and uncertainty for sex workers in relation to authorities (Khruakham & Lawton, 2012). The illegal nature of sex work and associated fear of prosecution likely impacts sex workers' decisions to access health services, negotiate condom use, prevent physical or sexual violence, and even participate in HIV policy or programme development.

Trafficking

Human trafficking is both a driver of sex work and a risk factor for HIV. Young women who are trafficked into sex work often have little or no human rights and are at greater risk of HIV due to sexual violence, intimidation and forced unprotected sex. The risk of HIV infection is even greater in the earlier months of sex work (Silverman et al., 2011). Trafficked sex workers often do not have the freedom of movement, so their ability to participate in HIV prevention or access testing is compromised (Decker, 2011). A national sample (n=815) of female sex workers in Thailand was studied to identify entry mode into sex work. Findings revealed that approximately 10% met the criteria for being trafficked into sex work (Decker et al., 2011). Of those who are trafficked into sex work, many are younger than 18 years of age (Decker et al., 2010). These young women are more likely, than those not trafficked, to have experienced sexual violence, condom failure or non-use, and abortion. Many of those trafficked into sex work come from neighbouring countries such as Laos, where poverty and unemployment rates are much higher (Molland, 2010). The Thai Government has responded to the need for repatriation and reintegration of trafficked migrant sex workers through providing programmes that allow for safe return home, life skills development, psycho-social assistance, protection, vocational training courses, medical care, rehabilitation and legal assistance (Jayagupta, 2009). The researcher noted however that there is no feedback mechanism for trafficked women to communicate about their situation and needs.

Migration

Migrant sex workers are at an even higher risk of HIV infection than their Thai counterparts, which is compounded by a lack of education, low rates of Thai literacy and poor access to information and services around HIV prevention

(National AIDS Prevention and Alleviation Committee, 2010). Migrants who lack documentation and/or are in the country illegally find it near impossible to obtain full access services such as healthcare or they receive reduced care due to stigma, discrimination, language and cultural barriers (Fuller & Chamratrithirong, 2009). Barmania (2013) stated that although the Thai health system has a good structure in place to care for Thai nationals, migrants are excluded from the system if they are not registered. Having refugee status, which is the case for many Burmese sex workers, also prevents access to the Thai health system. This clearly demonstrates the importance of not-for-profit organisations such as the Empower Foundation who provide health and legal services to all sex workers free of charge. In their 2012 report entitled: *Sex worker's research on anti-trafficking in Thailand*, the Foundation stated that their members include migrant sex workers from Laos, Burma, China and Cambodia. A study on Cambodian children working in a market in Thailand observed that the decision to migrate to Thailand was linked to household debt, family socio-economic status, and lack of education and family conditions (Sankharat, 2013). These children would initially work in trade activities and then progress to sex work from age 14 years where they could earn more money but were found to be at greater risk of developing drug addictions and/or contracting HIV (Sankharat, 2013).

Stigma and marginalisation

The WHO (2012) recommended that “health services should be made available, accessible and acceptable to sex workers based on the principles of avoidance of stigma, non-discrimination and the right to health” (p. 8). Despite this recommendation, recent research suggests that the delivery of health services for sex workers is not free from stigma and discrimination, and that this also contributes to community-based stigma and discrimination (King, Maman, Bowling, Morocco & Dudina, 2013). Further, in countries where sex work is illegal, sex workers experience stigma and marginalisation which can prevent them from accessing high quality health services (Ahmed, Kaplan, Symington, & Kismodi, 2011). Laws against sex work can also marginalise sex workers from engaging in safe sex practices, as carrying condoms can result in police harassment.

Violence

YWSWs experience sexual and physical violence leading to social isolation and poor mental health. In a study of 326 YWSWs in Goa, who experienced sexual or physical violence, 41.5% had attempted suicide (Shahmanesh, Wayal, Cowan, Mabey, Copas, & Patel, 2009). Trafficked YWSWs in Thailand are at a higher risk of contracting HIV due to violent rape, inability to refuse sex, lack of safe sex practices, unsafe drug use and lack of access to health care (Decker et al., 2011; Gupta, Raj, Decker, Reed, Silverman, 2009). Sadly, many sex workers consider violence part of the job or have little knowledge about their rights, putting them at further risk of abuse (Comack, & Seshia, 2010)

YWSWs in Thailand have been found to have little knowledge of the relationship between condom use and HIV (Moraros, Buckingham, Bird, Prapasiri, & Graboski-Bauer, 2012). One reason for low levels of knowledge is the lack of education discussed earlier (Nemoto et al., 2013). Sex workers have often missed out on education programmes provided by the school system. This may contribute to a low level of knowledge of HIV/STIs when they enter the sex industry. A positive correlation has been found between condom use and HIV/STI education among sex workers (Nemoto et al., 2013). Those with little knowledge of HIV are also less likely to access HIV testing services (Robertson et al., 2012). Adequate HIV knowledge however does not always translate to safe sex practices. Moraros et al. (2012) found that YWSWs in Thailand, despite their knowledge of HIV and the benefits of condom use, chose to use condoms infrequently, with the majority of participants (88%) citing reasons for non-use as condoms not being readily available and the cost of purchasing them. This demonstrates that even when HIV knowledge is present, external factors such as condom cost and availability, as well as preferences of clients, can prevent sex workers from engaging in condom use.

Drug Use

Injecting drugs users are one of the most-at-risk groups for HIV in Thailand. Underage sex work has been associated with using inhalants as first drug, forced first injection, number of drug treatment attempts and recent receptive syringe sharing (Goldenberg et al., 2012). A study on female injecting drug users found that HIV prevalence was higher among those under 20 years of age (Srirak et al., 2005). This may be due to the lack of knowledge around harm minimisation strategies. There are

also links between drug use and sex work: sex workers being more exposed to drugs, or drug users entering sex work to pay for their habit (Kang et al., 2011; Maher et al., 2011).

Place of work

As discussed earlier, the context of sex work in Thailand has changed from being predominantly ‘direct’ - where sex work is paid for and occurs at brothels or similar sex based locations; to being non-venue based - where sex work is negotiated at a range of other venues such as night-clubs, bars and karaoke clubs and hotels (Kerrigan et al., 2013). The location where sex work takes place has implications for HIV risk. For the context of this study, ‘place of work’ will be classified as brothel-based, non-brothel based, and non-venue based. Brothel-based sex work refers to sex work that is carried out in establishments designated for sex, including brothels and massage parlours, where there tends to be a greater likelihood of rules around condom use. In non-brothel based sex work, sex work is negotiated at venues such as bars or nightclubs, and occurs offsite; there is no requirement for sex workers to use condoms. Non-venue based sex work, which refers to sex work negotiated on the street or other public places or phone networks (Manopaiboon et al., 2013), puts sex workers at the greatest risk of HIV.

The contextual location of sex work can increase HIV infection risk with non-venue based sex workers having an 11 time greater risk of contracting HIV in comparison to those working from direct sites such as brothels (Nhurod et al., 2010). In terms of HIV prevention, non-venue based sex workers, unlike their brothel-based counterparts, are not required to undertake STI or HIV testing, are not supported to use condoms, and are less likely to have access to outreach services, free condoms and health services (Manopaiboon, 2013). Further, studies have found that without the supportive system of the brothel, indirect sex workers frequently engage in sex with customers under the influence of alcohol, that condom use is hard to encourage or enforce with clients and risk of sexual or physical violence is high (Decker et al., 2010; Nemoto et al., 2013).

Risk factors for HIV among YSWs in Bangkok have been found to be significantly varied between work sites. Working conditions among brothel workers were the worst, with long work hours, highest number of clients and lower remuneration. Due to the environment, bar workers frequently worked under the

influence of alcohol. Unprotected sex was high, with over 79% of massage and bar workers engaging in unprotected sex (Nemoto et al., 2013). Another Thai study found that brothel-based YSWs knew the benefits of condom use but adherence rates were low, with the daily condom versus client rate at 3.8 and 7.4 respectively (Moraros et al., 2012).

2.4 Conclusion

This chapter has shown that YSWs are situated within a context of poverty, educational disadvantage and gender inequality. The literature revealed that the factors putting YSWs at risk of HIV are wide and complex. A greater understanding of the current Thai context is needed to be able to identify new ways to address HIV among YSWs, including those most-at-risk of HIV such as non-venue based workers.

As the sex work environment is one that is constantly changing (Keerigan et al., 2013), HIV policy makers and programme planners must be aware and responsive to developing trends. The next section will focus on participation theories in public health and how they might relate to YSW and HIV policy and programme development.

Chapter 3: Participation theories, young women sex workers and HIV policies and programmes

3.1 Introduction

'participation is [...] the redistribution of power that enables the have-not citizens, presently excluded from the political and economic processes, to be deliberately included in the future'

(Arnstein, 1969, p.3).

The benefits of participation by the community in public health programmes, like those targeting HIV, are potentially far-reaching, according to much of the literature (Kako, Stevens, Mkandawire-Valhmu, Kibicho, Karani, & Dressel, 2013; Kim, Kalibala, Neema, Lukwago, & Weiss, 2012). For the case of YWSW, there is much to gain from their involvement in the development of HIV policies and programmes, such as more appropriately targeted HIV services.

By observing that YWSWs are articulate, knowledgeable and able to positively contribute to HIV policy discussions allows barriers to meaningful participation such as stigma to be addressed (Kuhlmann, Hastings, Narayanan, & Saggurti, 2014). The active participation of YWSWs in HIV policies and programmes may also provide an opportunity to involve sex work clients, who provide a unique insight into how these programmes could best work. Greater participation provides benefits to individual sex workers and clients in terms of empowerment and capacity building, but also helps to build and strengthen sex worker collectives, who are then better positioned to act on behalf of the individual. Most importantly, by involving YWSWs in the design of HIV programmes, programmes are more likely to be better suited to sex workers needs and produce better outcomes. YWSW involvement in designing and assisting with evaluation of HIV programmes will also help to address issues such as how to access hard to reach sex workers, or identifying research methods which are more appropriate for this vulnerable population.

Arnstein (1969), (as cited in Cornwall, 2011) in her ground-breaking work, defined participation as 'the redistribution of power that enables the have not citizens, presently excluded from the political and economic processes, to be deliberately included in the future' (p.3). Thai literature about community

participation is characterized by concepts such as self-determination, empowerment, decision making, community control and equality¹. Yet, meaningful participation is challenged by traditional cultural norms which discourage critical thinking and autonomy, promote hierarchy and marginalise vulnerable groups (UNDP, 2013; Weil & Romocki, 2006). In the context of YWSWs in Thailand, the research generally considers YWSWs a vulnerable group and this significantly affects their participation in community programmes. It is important to note that the definition of ‘vulnerable’ is hard to establish, as vulnerability is a socially constructed concept that can result from a number of factors (Moore & Miller, 1999). According to Flaskerud and Winslow (1998) vulnerable populations are those people or groups who have increased risk in relation to an adverse health outcome, alternatively Moore and Miller (1999) contend that vulnerable people are those who lack autonomy in decision-making, independence and self-determination. As a result, the participation of vulnerable groups such as YWSWs calls for a more sensitive approach, as opposed to traditional approaches that are designed for more autonomous groups. It should encompass strategies that protect their vulnerability, for instance, providing a physical space for participation that protects their anonymity.

In reality, community participation rarely occurs, and if it does, it routinely involves tokenistic approaches such as ‘consultation’ or ‘informing’ which are more decorative than true and meaningful forms of participation. Cornwall (2011) contends that participation should not be restricted to the sharing of information, but should extend to the sharing of resources, control, benefits and skills through decision making processes. Accordingly, participation has a definite and important role in the management of programmes as well as designing policy.

Internationally, there has been some commitment to improve HIV outcomes through greater community involvement. The Alma Ata Declaration of 1978, which was focused on the urgent need for primary health care, recognised that community participation in health care planning and implementation was a human right. Governments therefore had a responsibility to ensure that this was achieved (WHO, 1978). In 1986, the Ottawa Charter for Health Promotion identified five action areas

¹ The review of literature for this study was focused only on English papers and may exclude Thai papers which have not been translated. It is recognised that this is a limitation of the review.

necessary to achieving health for all, and recognised that ‘strengthening community action’ was key to achieving this goal (WHO, 1986). Community participation in public health aims for services to be delivered in a cost-effective, transparent and accountable manner, but most importantly, it helps to ensure those services are meeting the needs of those they target (Kamuzora, Maluka, Ndawi, Byskov, & Hurtig, 2013; Meetoo, 2013). Yet in reality, consumer participation approaches tend to be driven by those in power and often prioritise approaches such as ‘consultation’ (Shagi et al., 2008; Spicer et al., 2011) which is observed by Arnstein (1969) as being a form of tokenism. Today, patient participation in the health system is considered a right, rather than a privilege. Despite the challenges that exist to involving sex workers and other at-risk groups in HIV prevention measures, there have been some examples of success, to various extents. Community participation in public health measures such as those dealing with HIV are known to significantly improve public health outcomes, but are often ineffective due to established power structures and tokenistic participatory approaches. Within the unique context of YWSW in Thailand it is important to analyse the types of participation that may occur, their efficacy and also their relevance to the context of public health interventions in Thailand. The following section presents Thai concepts of participation. This is followed by a discussion of three key theories of participation and analysis of how they could be applied within the Thai context.

3.2 Thai concepts of community participation in health

Community participation in Thailand may be conceptualised in different ways. An early and successful example is a Community Capacity Building (CCB) project supported by the Sustainable Community Development Foundation (SCDF). CCB is a general health promotion concept based around a ‘bottom up’ or community determined process with the aim of developing community empowerment and competency as opposed to a top down, externally based approach where those in power impose their own agendas (Raeburn, Akerman, Chuengsatiansup, Mejia, Oladepo, 2006). CCB has been described as “the characteristics of communities that affect their ability to identify, mobilize and address social and public health problems; and the cultivation and use of transferable knowledge, skills, systems and resources that affect community and individual level changes consistent with public health related goals and objectives’ (McLeroy, 1998

cited in Goodman et al.,1998, p.259). CCB is strongly associated with various concepts such as empowerment, community control, self-determination, participation and equality (Raeburn, Akerman, Chuengsatiansup, Mejia, Oladepo, 2006). Studies of successful CCB often come from transitional economy countries where marginalised and disempowered communities are the focus. It must be reiterated that although true CCB is a community-determined process, health promotion professionals and others in authority frequently collaborate with to form partnerships with the communities that are ultimately in control of their own community capacity (CC) building process (Raeburn, Akerman, Chuengsatiansup, Mejia, Oladepo, 2006). The Rural Community Development Programme in Khon Kaen province is a dramatic and successful example of CCB in action. Farmers from this rural community 445km North-East of Bangkok have been suffering from a crisis involving low income, debt, crime, environment degradation and a wide range of health problems. Through a large network (2650 families), the pooling of local wisdom and formation of a strong community group allowed these farmers to address health issues within their community.

The Monks' Health Holistic Health Care Model, as presented by Buates, Chantachon, Paengsio & Kangrang (2010), is said to have been developed out of a process of community participation. Historically, monks could rely on the local community for healthcare provision. A shift in labour demands meant that communities could no longer provide the same level of care, resulting in a decline in monk health. Clearly, the health of the monks was important, but it is unclear as to whether or not the project was developed from a need identified by the monks, or if it was driven from the top-down. Also, the involvement of monks in the development of the model is unclear. The model presents the roles that different groups should play in working to address monk health. The monks are presented as having no involvement in developing plans, and are only responsible for engaging in activities related to their own health behaviour, such as exercising or attending check-ups. Qualitative research methods of focus groups, interviews and workshops were used, but the research findings did not present the voices of the monks. The paper showed that there was a lack of monk participation in the development of the model and a lack of opportunities in decision-making in relation to their health care. This may demonstrate that the 'Guidance-Cooperation Model' still prevails, a model which supports the notion that decision-making is left to the health-care provider,

and the patient participates by adhering to their treatment (Chunuan, Vanaleesin, Morkruengsai, Thitimapong, 2007). This demonstrates that this is not a model of community participation but an intervention being carried out by researchers and those in authority.

Another example of CCB participation is the Southern Thailand Empowerment and Participation (STEP) project, which was developed in 2009 and implemented by the Prince of Songkla University in 2010. The project aimed to bring government and non-government groups together to find solutions to achieving social cohesion and addressing the political and socioeconomic issues in the southern border provinces. (Government of Thailand and UNDP, 2010) The project was conceptualised using the UNDP's Community Security and Social Cohesion Policy. However, given the high government sensitivity in regards to the political crisis that existed at the time, it may not have been an appropriate framework to use, as the community were reluctant to participate in some project aspects. The project was intended to empower communities and civil society networks through participatory approaches and build the capacity of the local authorities (Government of Thailand and UNDP, 2010). While the project had been successful in expanding civil society networks and community-based organisations, the capacity of these organisations remained low due to resource constraint and there was a lack of joint decision making opportunities (UNDP, 2013).

Also out of Prince of Songkla University is an initiative called the "Pat(t)ani Peace Process. Launched in 2012, it provides a space for civil society groups, academics, local representatives and religious leaders to come together to analyse the current conflict situation in Southern Thailand and develop a solution. This process is supported by parallel systematic assessment and a reflection process that is driven by a group of scholar-practitioners. The members of the group are required to represent the position and views of their networks (UNDP, 2013). Pat(t)ani Peace Process involved measures to ensure transparency and accountability of decision making, factors that are often lacking from participatory processes. It is important that measures such as these are also adopted for YWSW participation so that their participation is not regarded as a 'rubber stamp' exercise. This makes the Pat(t)ani Peace Process a good example of participation.

Another example of participation is the Village Based Quality of Life Project (PHANOM), which is due to conclude in 2014 and provides grants to villages to implement community development projects. Project development is supposed to involve the whole community and project planning should occur at village meetings and ‘participatory planning’ sessions. Instead, project management is controlled by the village ‘elite’ and their family members, and community participation is manipulated to their advantage, but not letting community members speak at meetings or not presenting the true essence of their opinions. Some community members are also alienated by the participation process as meetings are conducted in Thai, yet some villagers only speak Malay. Traditional customs were observed which limited participation, such as “phu noi tong kaow rob phuyai” (“little people should respect important people”) and “kraenjai” (“deference to people who have power or authority”). These customs not only prevented community participation, but also ensured that the village ‘power-base’ was maintained, leaving the community in a position of powerlessness.

This project shows one of the key challenges for participatory processes in Thailand: the embedded nature of traditional norms of hierarchy in Thai society. This is particularly relevant for the case of YWSW who hold a low position in Thai society, which already puts them at a disadvantage, so their views may not be considered by decision makers or those with higher social status.

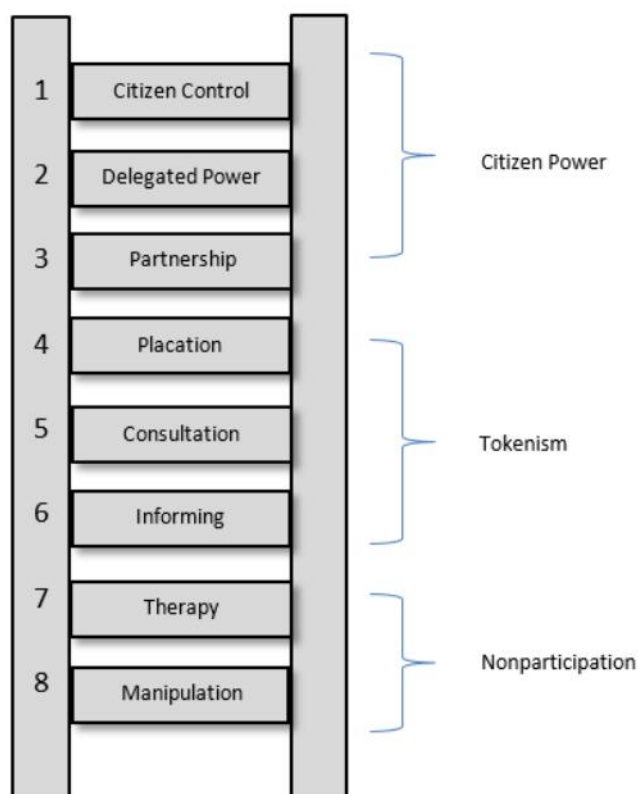
3.3 Participation theories and frameworks

Perhaps the most widely known and influential framework on participation globally is Arnstein’s Ladder of Citizen Participation (Arnstein, 1969); one that has formed the basis of much theory around the topic to date. While Arnstein is more commonly referred to as a social work professional, her experience of participation is also health-related. Throughout her career, her main focus was in regards to the empowerment of individuals and community by directly involving them in planning and decision making (LeGates & Stout, 2011). After working in various social work/community support roles, Arnstein joined the staff of the Kennedy Administration’s Commission in 1963, where she worked with communities to improve job prospects, housing and schooling (LeGates & Stout, 2011). While working at the Department of Health she developed a strategy to de-segregate hospitals and in 1966, was Chief Advisor to the Model Cities Program at the US

Department of Housing. Her last role was as Executive Director of the American Association of Colleges of Osteopathic Medicine, where she worked for 10 years (LeGates & Stout, 2011). In 1969, 'A Ladder of Citizen Participation' was published in the Journal of the American Planning Association with an aim to address the following question: "What is citizen participation and what is its relationship to the social imperatives of our time?"

The Ladder of Citizen Participation (see Figure 1) conceptualises the forms of participation that might commonly occur. These forms of participation are described on a continuum ranging from the least empowering and manipulative forms through to something more akin to true empowerment in the forms of partnership, delegated power, and citizen control. Within this model participation 'rungs' on the ladder can be grouped into themes of non-participation, tokenism and citizen power (Arnstein, 1969).

Figure 1. *Ladder of Citizen Participation*



Through Arnstein's ladder, it is made clear that community participation takes many forms and is ultimately dependent on the willingness of those in positions of authority to share power and resources. The ladder assumes that as people progress up the ladder, they have access to greater power and decision

making opportunities, thus resulting in greater participation. Yet, Cooke and Kothari (2001) observe that the place of power in the theory of participation has been simplified, and that in reality, power can be expressed in many ways. Power conflicts can exist in many forms: young sex worker versus old, brothel owners versus sex workers attached to the brothel, sex workers versus clients/health workers.

Section 3.1 of this thesis outlined that YWSW participation is beneficial to the wider community, clients, individual sex workers and sex worker collectives. Interestingly, Arnstein's Ladder of Citizen Participation indicates that these benefits are sometimes not experienced due to established power structures. This point is reinforced by Richards et al. (2007), citing Cooke and Kothari (2001), who notes, 'participatory approaches do not always empower but may unwittingly serve to legitimise and support the status quo' (p.16). By observing YWSW participation through the lens of Arnstein's ladder of Citizen Participation, it becomes apparent that it may often be in the best interests of authorities to limit debate on health interventions so as to not have their decisions and false promises challenged. By limiting debate, those in positions of authority can avoid confronting the broader issues that contribute to HIV, such as stigma, legislative bias and pervasive violence. Additionally, participatory approaches which are merely forms of "tokenism" or "non-participation", do not enable a meaningful dialogue between YWSWs and the established power holders. As a consequence YWSWs are not in a position to demonstrate that they are in fact knowledgeable and can contribute meaningfully to the debate on public health interventions. As these forms of high level participation are not founded on established relationships of trust, it is unlikely that sex workers would be willing to support the involvement of their clients, thus resulting again in a lack of meaningful participation. In order to act on behalf of sex workers, collectives must be able to speak for all sex workers including those who are most voiceless and marginalised within their communities. Without relationships of trust or a mandate from sex workers themselves, there can be no real participation. Despite the fact that the involvement of sex worker collectives in the development of interventions is a practical example of Arnstein's 'citizen control', these groups may not have a sufficiently strong mandate from the very people they are supposedly acting on behalf of, making the participation framework inherently weak from the outset.

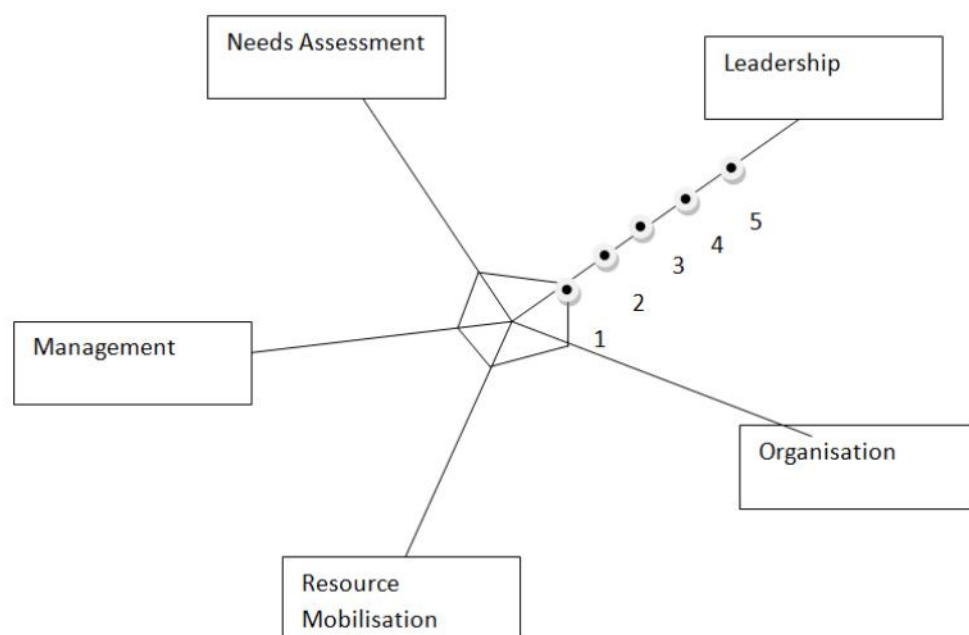
Even at the top most rungs of the ladder, such as the ‘partnership’ level, the increase of power may not necessarily result in greater YWSW participation, due to a lack of trust in authority. The factors that put YWSWs at risk of HIV such as violence, stigma and the illegal nature of sex work, create an environment where YWSWs do not trust authorities (Odinokova, Rusakova, Urada, Silverman, & Raj, 2014; Scorgie, Vasey, Harper, Richter, Nare, Maseko, & Chersich, 2013). For this reason YWSWs may be sceptical of opportunities that encourage their participation; for fear that the authorities may have ‘hidden agendas’. A reduction in community stigma was mentioned earlier as a possible benefit to YWSW participation. This would indicate that stigma is a barrier to participation, a consideration that is not addressed in Arnstein’s ladder. Issues of stigma regularly prevent sex workers from accessing HIV testing services (King, Maman, Bowling, Maracco, & Dudina, 2013) so it is not unreasonable that negative attitudes could permeate into opportunities for participation. These challenges demonstrate that efforts to increase YWSW participation call for long-term input to allow for those in power to gain greater sex worker insight. These valuable insights would result in increased empathy, reduce negative attitudes towards YWSWs and help to build much needed rapport and trust.

Rifkin et al. (1988), also a pioneer in the development of community participation theory, describe participation in health as “a social process whereby specific groups with shared needs in a defined geographical area actively pursue identification of their needs, take decisions and establish mechanisms to meet their needs’ (p. 933). Yet, this definition (which has similarities with Arnstein’s notion of ‘Citizen Control’) is far from most participatory approaches currently in use for HIV health interventions, which in practice do not provide a ‘space’ for community needs to be addressed. Accordingly, it could therefore be argued that most participatory approaches, such as those presented in Arnstein’s ladder and Rifkin’s model, are not true examples of participation but mere attempts for those in power to preserve a culture of non-participation. Participatory approaches such as ‘consultation’ are also typically ‘one-off’ exercises that lack planning and careful consideration of the needs of those whom they are consulting with (Arnstein, 1969). Those developing participation frameworks for HIV health interventions should consider if they have the considerable resources, time and effort required to engage communities in meaningful participation as opposed to tokenistic approaches, as poorly planned efforts can produce negative effects such as significant loss of time, frustration of

process, loss of control and loss of anonymity (Flicker & Guta, 2008). Consequently, this can significantly affect the relationship of trust between those designing the programme and the YSWs. As already discussed, YSWs, who are already vulnerable, require extra care to ensure that they are not exposed to greater harm through poor planning, or that extra precautions are observed to reduce the risk of harm, for instance, a loss of anonymity. Poor planning may even unintentionally further marginalise those hard-to-reach sex workers such as non-brothel workers, who have greater needs in regards to HIV prevention (Manopaiboon et al, 2013).

Rifkin et al. (1988) developed a method for assessing community participation in health programmes using a pentagram model (Figure 2), presenting five factors which influence the participation process: needs assessment, leadership, organisation, resource mobilisation and management. As shown in Figure 2, each factor is presented along a continuum. The level of participation for each factor is assessed through a series of questions and the final score is then marked on the model. The purpose of this model is to provide a visual concept of how the level of participation and the process of participation changes over time, and also to help planners to identify where to prioritise resourcing.

Figure 2. *Pentagram Model of Community Participation*



Like Arnstein's ladder, this model was developed for the general population and thus is applicable, but lacks specific relevance for YSWs. As discussed in Chapter one, most-at-risk groups such as sex workers are at a distinct disadvantage due to the diminishing financial resources allocated to them. Without a significant financial base, it is difficult to expect such groups to mobilise resources for participation to any great extent.

Thai researchers argue that people describe their experiences using concepts and terms that are relevant to their social context (Liamputtong & Ezzy, 2005). This demonstrates the importance of using contextually relevant tools when measuring participation. For this reason, Rifkin's Pentagon Model of Community Participation might not be appropriate for use among YSWs.

Rifkin has designed his framework to evaluate participation within a health intervention, and so it fails to capture any progress made to address broader social factors, such as stigma, which may hinder participation. Failure to address broader social impacts within a participation framework means that, Rifkin's Pentagon Model of Community Participation could be used to maintain the status quo. For instance, YSWs participation could be indicated by their membership on a decision-making committee, but fear or lack of trust with decision-makers could mean that they take a passive involvement. For YSWs, this could create a negative experience of participation, reinforcing their position of voicelessness and an inability to change their environment.

The forums that are provided for participation are often dominated and reflective of those who are considered the most powerful in society. This is a limitation for Arnstein's (1969) ladder of citizen participation and the Pentagon Model of Community Participation, as they rely on community representatives who are responsible for communicating the position and needs of their communities. Yet YSWs are diverse and have varying needs in regards to HIV prevention and demonstrates the need for multiple opportunities for participation, where YSW can represent themselves in ways that protect their anonymity but also approaches which utilise the power of sex worker collectives. Wilcox (1999) built upon Arnstein's framework and developed the 'Ladder of Participation' which identified five levels

of participation, namely: information, consultation, deciding together, acting together, and support individual community initiatives. The framework suggests that different levels of participation are appropriate for different contexts and the degree of participation afforded to community is determined by the needs of the decision makers (Wilcox, 1994). This again demonstrates the subtle ways in which organisations can exert power and control over community participation, limiting possible opportunities for community empowerment, especially for those who are most marginalised from society, such as YWSWs. As the focus of this framework is on initiator needs, YWSWs lack opportunity to increase their capacity and feelings of empowerment through activities that promote skill development. This approach, like others discussed in this section, prevent YWSWs and those in power from engaging in dialogue. Yet for dialogue to occur, YWSW input must be valued and there must be greater understanding of their increased HIV risk, and what prevention efforts have to gain from their involvement.

The Ladder of Participation (Wilcox, 1999) also lacks transparency on the aims of participation, which has implications for building trust and rapport with YWSWs. If there is transparency around why they are participating and who will benefit from the participation, YWSW are more likely to feel empowered by the participation process. If YWSWs feel empowered, they will be more likely to take ownership over implementing these programmes or policies, which may in turn lead to greater collective action (Galavotti, Wheeler, Kuhlmann, Saggurti, Narayanan, Kiran, & Dallabetta, 2012). YWSW participation should thus be built on efforts to improve trust and rapport and a dialogue that promote openness and transparency.

Yet, it is an understanding of the social context – in this case of Thailand - that provides the foundation for this dialogue. Campbell and Cornish (2010) describe the social context as being made up of the symbolic, material and relational realms. The symbolic context refers to the meanings, ideologies, and worldviews that relate to the social environment in which people live and how they see others and themselves. The material context is made up of two concepts which are closely related to health. The first is resourced-based agency which relates to how people have access to money, food, paid work or funding for development projects, and the second concept relates to the opportunities that people have to put those resources or their agency into practice. The relational realm refers to many factors which have

great implications for meaningful dialogue (Campbell & Cornish, 2012). It includes such factors such as democratic and accountable leadership, recognizing people's rights to fight for political rights and advance their economic position. It also relates to the ability for the project to build social capital, both within the community and between the community and the power holders. Yet earlier examples of participation in the Thai context demonstrated community participation is challenged by hierarchical power structures and an inability for decision-makers to hand over decision-making responsibilities to the community (UNDP, 2013). This has implications for the participation of YSWs who have low social status in Thailand.

The challenges of applying the traditional participation approaches set out above to at-risk communities has been observed by Conn, Modderman and Nayar (2013) who argue that 'despite the positive discourse, methods for introducing participation into a health context are poorly understood; do not fit within the dominant biomedical paradigm (which is expert-driven); and there is typically a lack of commitment by health policymakers to provide resources and create a space for communities to have a say in program development'. The space that is provided for YSW participation is an important consideration. It must be 'youth friendly', given the focus of the sex industry on young women, and provide for non-traditional models that draw upon the strengths of young people and account for these challenges (Gibbs, Campbell, Maimane, & Nair (2010). Other more recent and more dynamic participation approaches that involve sex workers directly in the conception and championing of a project, are related to 'sex worker leadership', an important factor in community based empowerment approaches to HIV (Kerrigan et al, 2013). Through their collective action and voice, YSWs are granted greater access to resources, human capacity and gain more power to influence HIV policy and planning processes. Instances where sex worker collectives have partnered with government have shown to have the greatest impact on HIV prevention (Kerrigan et al., 2013). For instance, the Sonagachi Project in India which is discussed in the following section resulted in expanded condom use, an improvement in HIV knowledge and increased testing and treatment facilities. Sex worker collectives are often crucial in the recruitment of hard-to-reach sex workers into research/HIV initiatives as noted by (Bradley et al., 2012) in his research on condom breakage among Indian sex workers.

3.4 Community and sex worker participation in HIV policies and programmes

This section relates to examples of community and SW participation, drawing on examples in Thailand. Examples of participation in HIV programmes in Africa and India are also discussed as they relate to YSWs or other vulnerable communities, so have relevance to YSWs in Thailand.

In Thailand, there has been some commitment by government to incorporate community input into health care planning. The National Health Assembly, founded in 2008 and based on the World Health Assembly, was an attempt for policy planning to involve the input of the most marginalised groups. The Assembly is made up of representatives from government, parliament, universities and civil societies, and agendas are put forward by these representatives on behalf of their networks and constituencies (Kanchanachitra, 2010). This kind of approach is problematic in that it may result in those with more power manipulating the planning process to suit their needs. Furthermore, it does not incorporate mechanisms to support representatives to ensure that the views and concerns of marginalized groups are heard. Akin to the framework proposed by Wilcox (1994), the Assembly is at risk of only presenting the views of those who hold the most power in society, and will fail to reach those who experience the greatest health inequalities such as YSW.

An intervention in North-East Thailand has shown that it is possible to involve marginalised groups in a meaningful way. The study involved community members (including those living with HIV) to develop and evaluate a project aimed at reducing HIV stigma and increasing HIV knowledge within the broader community. The study indicated a significant increase in HIV knowledge with a decrease in stigma (Apinundecha, Laohasiriwong, Cameron, & Lim, 2007), and therefore demonstrates how community participation can address broader social issues such as community stigma which is a risk factor for HIV. This study demonstrates an example of Arsteins' concept of 'partnership' as it involved researchers and community working together at all aspects of programme development, implementation and evaluation.

An example of sex worker participation in Thailand is the 100% condom programme, which was focused on the enforcement of condom use, but lacked

meaningful sex worker participation. Sex workers were expected to attend meetings and implement the ‘no condom – no sex’ policy (UNAIDS 2000), but were not involved in the design of the programme (Kerrigan et al, 2013). While the ‘no condom – no sex’ policy resulted in a power shift, this was not from clients to sex workers, but from clients to police and brothel owners, those well known for the exploitation of sex workers (Kerrigan et al, 2013). It is important to note that the 100% condom programme was officially implemented around the same time that the Prevention and Suppression of Prostitution Act, B.E. 2539 (1996) was enacted, a law which made the open soliciting of sex work illegal, thus encouraging brothel-based sex work. This would have undoubtedly elicited greater political support for the programme, further marginalising non-brothel based sex workers. According to Rojanapithayakorn (2006), the 100% condom programme was empowering for sex workers as it provided them with the ability to say no to clients who did not want to use condoms. However, some sex worker collectives such as ‘Empower’ argue that sex worker involvement was coercive in nature and often even abusive as police were responsible for enforcing condom use, leaving sex workers vulnerable to exploitation (Kerrigan et al., 2013). On the surface, this programme would appear to fall under the ‘partnership’ rung of Arnstein’s (1969) ladder, but in reality it was coercive in nature and should therefore be associated with the bottom rung of the ladder, known as ‘manipulation’, a form of non-participation. The 100% condom programme example shows the importance of understanding the context of participation and asking questions such as ‘who is participating?’, ‘why are they participating?’ and ‘who is to benefit from this participation? Without this knowledge, the potential contribution of the community is diluted (Dyer, 2004).

Peer education is a widely used strategy for addressing HIV among sex workers (Ford, Wirawan, Suastina, Reed, & Muliawan, 2000; Ghose, Swendeman, George, & Chowdhury, 2008; Kerrigan, Telles, Torres, Overs, & Castle, 2008) and has been implemented with some success in Thailand since the mid – 1990’s (Van Griensven, Limanonda, Ngaokeow, Isarankura Na Ayuthaya, & Poshychinda, 1998; Visrutaratna, Lindan, Sirhorachai, & Mandel, 1995). Peer education is a relatively ‘downstream’ approach as it aims to address the individual’s behaviour (Bekemeier, 2008). In relation to HIV prevention, the peer education process generally involves a more experienced and knowledgeable sex worker, educating another, typically younger sex worker around HIV and STIs. Through peer education, the educator

learns more about current challenges facing young sex workers and the person receiving the education will learn how to protect herself and her partners. A sense of empowerment is also achieved through increased education and greater control over one's life (Wiggins, 2012). Commenting on the limitations of peer education, Cornish and Campbell (2009) argue that “rarely has peer education been found to produce dramatic, consistent positive effects. More often, programs produce an inconsistent pattern, with small effects” (p. 124). Previous research has indicated that peer education is commonly a ‘top down’ approach to participation in HIV prevention, often initiated by governments, but involving communities in the delivery aspect of the programme (Van Rompay, Madhivanan, Rafiq, Krupp, Chakrapani, & Selvam, 2008).

Also, despite the intention for peer education programmes to increase participation, the success of these programs is largely dependent on the cultural, social and legal contexts in which they are delivered (Lambert, Debattista, Bodiroza, Martin, Staunton, & Walker, 2013). As sex work is illegal in Thailand, many sex workers are fearful of the police and their employers (Decker, 2010), therefore consideration needs to be given to how to protect the anonymity of these women, whilst still providing opportunities for participation. The Sex Worker Leadership Initiative, based in Africa and known as “Pow Wow”, is the perfect example of sex worker collectivism. Not only does it teach sex workers practical skills around activism, leadership, organisational development and personal wellbeing, but it also seeks to increase knowledge on the theoretical concepts and frameworks that underpin activism and advocacy. This initiative also focuses on providing ‘safe spaces’ for sex workers to participate in learning and the building of networks between sex workers and potential allies to further the sexual rights agenda in Africa (Fahamu, 2014). Pow Wow is an example of an upstream approach to HIV prevention, as it seeks to address the broader issues that act as barriers to HIV prevention such as gender inequality.

The upstream/downstream approach is a metaphor often referred to in public health discourse to describe the types of approaches used to address health disparities. An upstream approach focuses on addressing the health issue at its source to prevent it from occurring or reoccurring, while the downstream approach addresses the health issue once it has occurred (University of Ottawa, 2014).

Another example of an upstream approach and one which demonstrates community leadership is the 'Treatment Action Campaign' (TAC) in South Africa, which was founded in 1998 by a group of HIV positive young women. Despite a lack of knowledge of public health and political processes, these women were very successful in developing an influential activist lobby for young women, focused on ensuring access to treatment, care and support services for people living with HIV and the development of campaigns to reduce new HIV infections (Campbell, Cornish, Gibbs, & Scott, 2010; Heywood, 2009). The TAC and Pow Wow initiatives are examples of the 'social movements' model of participation. According to a definition provided by McAdam (1982) social movements are "those organized efforts, on the part of excluded groups, to promote or resist changes in the structure of society that involve recourse to non-institutional forms of political participation" (p. 25).

This model seeks to provide communities with a mechanism for reforming systems and structures that prevent equality, which is also a driver of sex work. The TAC demonstrated that it is possible for marginalised groups to influence high level HIV policy and programme development through collective activism. As such, the TAC falls within the 'Citizen Control' rung of Arnstein's (1969) ladder and is also an example of 'true empowerment', demonstrating how relatively powerless people can work together to increase control over their lives. It could therefore be said that through collective action and voice, the power imbalances were shifted. This shows that approaches which follow a 'social movements' model are not influenced by power to the same extent as the frameworks presented by Wilcox (1994) and Arnstein (1969) which even at the highest levels of participation, still allow governments to hold some power in decision making. The 'social movements' model adopted by TAC also differs from Wilcox's (1994) framework in that it relies on the personal commitment of those participating and seeks to address often broad issues that affect the daily lives of people. This differs from the model proposed by Wilcox (1994) which has a narrow focus and a view to only meet the needs of those in power with no interest in addressing the real issues faced by communities.

The Sonagachi Project, which was based in Kolkata India, is perhaps the most well-known example of how sex worker leadership and participation can address public health concerns such as HIV, once appropriate mechanisms are put in

place to support their participation (Kerrigan et al., 2013). The project showed that it is possible to address HIV using both community driven and government-led approaches. Sex workers raised awareness around labour rights, made changes to the working environment, expanded condom use and improved HIV knowledge; whilst the government initiated surveillance systems and increased testing and treatment facilities (Kerrigan et al., 2013). The Sonagachi Project focused on four main domains for sex worker participation which included (1) participating in accessing project services; (2) participating in providing project services; (3) participating in shaping project workers' activity; (4) participating in defining project goals (Cornish, 2006). Those who participated in the intervention showed varying levels of participation and some preferred to keep their participation to a minimum, for instance accessing project services rather than participation in developing the intervention. This approach to participation, as Cornish (2006) suggested, is in contrast to the Arnstein's ladder of participation which refers to this kind of activity as a form of non-participation. However these forms of participation may have a place in sex worker communities and may appeal to those who would prefer their counterparts to take lead. The Sonagachi Project differs to the 'social movement' model presented by TAC in that it presents a model of 'community-led structural interventions' which combines community participation and engagement with structural interventions which have been developed by researchers or programme planners (Ghose, Swendeman, George, & Chowdhury, 2008). While this model provides opportunities for various types of participation, those initiating the participation have ultimate control over the outcome. As such this model does not fall within 'citizen control' and is instead an example of 'partnership'. Campbell and Cornish (2012) contend that the project's success was due to its skill in harnessing the personal, political and economic interests of those in power. This demonstrates that for the case of YWSW in Thailand, simply having 'dialogue', and the ability for authorities to have insight and understanding is not sufficient. Dialogue must therefore take place with an understanding of the social context.

3.5 Conclusion

The meaningful participation of YWSWs in HIV policies and programmes is key to addressing those risk factors mentioned above, but may also help to address the drivers of sex work. Sex worker participation in HIV policies and programmes

has been shown to increase feelings of empowerment, increase HIV knowledge (Cornish & Campbell, 2009), reduce HIV rates (Sweat et al., 2011) and result in collective action (Chakravarthy, Joseph, Pelto, Kovvali, 2012). It gives policy makers and programme developers an opportunity to have meaningful dialogue with communities and a chance to explore the social, cultural and legal barriers that exist to addressing HIV for that specific community. Greater involvement of sex workers in HIV prevention will also help to break down negative community attitudes towards sex workers, making it easier for them to access much needed services, such as HIV testing. In light of these benefits, YWSW participation should not just be as a problem solving exercise, but a necessary component in the development, implementation and evaluation of HIV policies and programmes.

There are various ways in which communities can participate in decision making and this is often shaped by those who hold the greater power, and the willingness of those in power to share that power with communities. Arnstein's (1969) framework drew the link between participation and power, describing how power influences different levels of participation. This link demonstrates that participatory approaches, even at the highest levels of the ladder, are not immune to power dynamics. While a number of traditional participation frameworks are useful in describing the way in which power influences and can drive participatory approaches, their applicability for the sex worker context is limited. These frameworks have been developed for use among the general population and therefore their relevance for most-at-risk groups such as YWSWs is questionable, as YWSWs are communities are not harmonious groups, homogeneous in nature (Cornish, 2006). Further, they fail to recognise the power relations and conflicts that exist even within marginalized communities.

In Thailand, the 100% condom programme, showed limited sex worker participation, lacked to input of sex worker-led organisations and has been described by some sex worker collectives as be coercive in nature (Kerrigan et al., 2013). Peer education was another example of how sex workers in Thailand participate in HIV prevention and has been successful in improving HIV knowledge and perceived vulnerability (Van Griensven, Limanonda, Ngaokeow, Isarankura Na Ayuthaya, & Poshyachinda, 1998) but has been criticized for its inability to show a reduction in HIV (Medley, Kennedy, O'Reilly, & Sweat, 2009), be sustainable (Cornish and

Campbell, 2009) and be initiated by the community (Mason-Jones, Mathews, & Flisher, 2011; Van Rompay, Madhivanan, Rafiq, Krupp, Chakrapani, & Selvam, 2008).

While some examples of sex worker participation were cited in the literature, this review has established that meaningful participation of YWSWs in HIV policies and programmes is lacking (Kerrigan et al., 2013) and does not fit within traditional participation frameworks. As such, alternative models for participation that meet the unique needs of YWSWs should be explored, such as approaches which focus on sex worker leadership and collectivism, or those that create ‘new spaces’ for YWSW voice. The following chapter will describe and discuss the methods and methodology used in the investigation of this research.

Chapter 4: Young women sex workers' participation in HIV policy and programmes in Thailand: a study design

4.1 Developing the research

The current study aimed to explore YWSW's participation in HIV policies and programmes in Thailand.

The main sub-questions that were used to guide this research were:

- Do YWSWs think that participation in HIV policies and programmes is important and if so why?
- What is the extent of current participation of YWSWs in HIV policies and programmes?
- What are the barriers and future opportunities for YWSW participation?

In the previous chapter, the literature in relation to YWSWs participation in HIV policies and programmes was critically discussed. This chapter describes the research process undertaken to answer the research question: To what extent do YWSWs in Thailand participate in HIV policies and programmes? This chapter will include a discussion of the qualitative methodology and method used to provide a suitable lens for examining the topic.

This research was conducted in partnership with Mahidol University's Institute for Population and Social Research (IPSR) in Bangkok. The study is part of a broader research project which aims to evaluate the *National HIV Prevention Program among Most at Risk Populations, Prisoners and Migrant Workers* (Institute for Population and Social Research [IPSR], 2013). IPSR were commissioned by the National Committee for the Advancement of AIDS Prevention and National AIDS Management Center (NAMC) of Thailand to conduct the evaluation; which took place between 2010 and 2013. The objectives of the evaluation were:

- to evaluate the quality, coverage and efficiency of HIV prevention for key affected populations and prisoners

- to promote the use of the evaluation findings to inform the design of strategies, implementation and refinement of interventions supported by the Global Fund.

The IPSR study aimed to answer, among others, the following research questions:

- Are all interventions being implemented as planned?
- Are intended interventions reaching the intended and right clients?
- Are interventions being implemented according to an integrated defined package of HIV prevention services, and defined standards of quality; and if not, what is missing and why? (IPSR, 2013)

In the IPSR study, female sex workers (FSW), men-who-have-sex-with-men (MSM) and people who inject drugs (PWID) are referred to as key affected populations (KAP). Three provinces were selected for the FSW and MSM studies and two provinces for the PWID study. The location of the provinces was kept anonymous, except for Bangkok, the capital city, as the Bangkok's unique and large and diverse population would make it easy to identify. In total, 1200 FSW participated in the study, 400 from Bangkok, 400 from Province A and 400 from Province B.

The findings of the IPSR study will be used to inform the evaluation of the 5-year national AIDS plan which commenced in 2012. This current study of participation contributes to the IPSR study as it provides an analysis of one of the research questions that the IPSR study attempts to answer, which was: "what is the extent of participatory involvement of KAP in planning and evaluating services?" This research question helps to address the first objective of the evaluation around implementation, as stated above.

As a foreigner who had limited knowledge of the topic and context of Thailand I knew that it would be difficult to research YWSWs. Through IPSR, I was introduced to SWING, an organisation based in the major tourist destinations of Thailand; namely are Bangkok, Pattaya and Samui. SWING provides general education, health education, outreach activities and other projects that aim to

empower sex workers. The organisation also works at the local and national level, advocating for the rights of sex workers. Currently 80% of SWING's staff have previously worked as sex workers at some point in time (Service Workers in Group, 2014). Formed in 2004, SWING's initial focus was to address STIs and HIV rates among male and transgender sex workers and MSM, with funding support from US Aid and Family Health International. SWING have now expanded to provide support to all sex workers and are funded predominantly by the Global Fund. It was the organisations good reputation and experience amongst YWSWs that enabled me to promote and conduct my research with this most vulnerable group.

4.2 My role as the researcher

Neergaard, Olesen, Andersen and Sondergaard (2009) argued the analysis of qualitative descriptions will always be influenced by the perceptions, previous experience, sensitivities, and beliefs of the researcher. Therefore the researcher cannot be separated from the research process. However, all writing is 'positioned' within a stance, and researchers must account for this and be open about it in their research (Campbell, & Machado, 2013). For this reason, I outline what has brought me to conduct this piece of research in the section that follows.

Through my various roles as a public health practitioner, I have developed a passion for community participation. I enjoyed learning about different cultures and needs of the communities I have worked with. I have used their cultures, experiences and views on health to inform my work. This passion led me to be involved in voluntary roles related to community development. Through my work experiences I have learnt about the role that public health professionals can play in helping to build community capacity. One such example I encountered, which highlighted the benefits of community participation, was in regards to regional gambling policy in Auckland. Community members in South Auckland wished to take action in reducing the number of poker machines in their communities but were unsure of how this could be achieved. I worked with these communities in providing technical assistance on how to write submissions to local government and advice on what data could be used to support these submissions. The project resulted in local government amending their gambling policy so that over time, the number of 'pokie' machines would be reduced.

In my roles I discovered that marginalised groups face many challenges in having their voices heard. For instance, in working with an alcohol community action group, I realized that the community felt disempowered regarding being able to change the density and the location on alcohol outlets in their neighbourhood. They were also unfamiliar with government processes and felt that the government would not be interested in hearing what they had to say. I have also seen examples of a community action group in East Auckland developing community action ‘fatigue’ from countless efforts to make changes to their environments resulting in only minor changes. This is also an example of the disconnect that sometimes exists between community expectation and the real extent to which communities can make a difference. As most members of the group worked full time, the resources that they were expending to be part of the group took its toll and the group lost many members. I have also learnt about the role that communities can play in programme development. In Perth, I worked with a group of Aboriginal women and helped them to design their own physical activity and nutrition programmes which were influenced by their traditional values and concepts. This resulted in them feeling more empowered over taking responsibility for their health.

4.3 Methodology and methods

This study uses a qualitative descriptive methodology which is an approach that can capture the ‘lived experiences’ and world-views of people (Bogdan & Biklen, 2007). The advantages of using a qualitative descriptive methodology in relation to policy research is that it enables a deeper examination of the situation and therefore can help to assess the issues and needs of a particular community. Thus, the social context, as described in Chapter 2, is very relevant to the issue of participation and qualitative research. Studies that are based on a qualitative descriptive methodology aim to collect data and present findings in ordinary language, with minimal interference and interpretation from the researcher (Sandelowski, 2000). This view is also in-line with the positivist paradigm which seeks to “minimize the interactions with and effects on the subject matter of the research” (Lapan, Quantaroli & Riemer, 2012, p. 7).

Yet, this research is focused on YWSWs who are a vulnerable group. The definition of ‘vulnerable’ is hard to establish, as vulnerability is a socially constructed concept that can result from a number of factors (Moore & Miller, 1999).

According to Flaskerud and Winslow (1998) vulnerable populations are those people or groups who have increased risk in relation to an adverse health outcome; and Moore and Miller (1999) contended that vulnerable people are those who lack autonomy in decision-making, independence and self-determination. In studies which involve groups who are considered to be ‘vulnerable’, there are a greater number of ethical issues to consider for ensuring the safety and welfare of participants (Liamputtong & Ezzy, 2005). Consideration should be given to ensure that vulnerable participants are not further marginalised by the research process and this involves careful planning and consideration around what methods are used and how data is collected to ensure that participants are not further silenced and that they are provided with a really good space to speak (Liamputtong, 2007). Qualitative research methods are appropriate for use with vulnerable populations as they provide researchers with an opportunity, although this might be somewhat limited, to hear the voices of participants and provide a ‘window into lives that might be very different to their own’ (Liamputtong & Ezzy, 2005, p. 205). Yet, the ability for participants to have their voices heard is dependent on the level of trust and rapport that has been developed, the methods used to collect data, and how data is then interpreted. In this study, a culturally matched research assistant was used, which, as Berg (1999) suggested, may help to encourage participation as the research assistant has an increased ability to build rapport with participants.

Another challenges lies around the presentation and interpretation of findings. Sandelowski (2010) noted that some researchers have misunderstood qualitative description to mean that data should be presented in un-interpreted quotation form, on the premise that the data should speak for itself. Researchers must therefore be able to strike a balance between interpretation and description, so that the voice of participants can be heard. The sensitive nature of researching vulnerable populations in health research requires a research method which allows participants to feel comfortable, in their ‘own space’, under conditions that encourage full participation (Liamputtong & Ezzy, 2005). Data collection techniques in qualitative descriptive studies tend to focus on the “who, what, and where of events or experiences, or their basic nature and shape” (Sandelowski, 2000, p. 338). In-depth interviews, such as semi-structured interviews, are often utilized in research with vulnerable groups (Liamputtong & Ezzy, 2005) but this method is not without criticism. It is sometimes referred to as a “hit and run” approach to data collection (Booth & Booth, 1994, p.

417), but in reality, it is an approach which requires careful planning. This must be a consideration for researchers who are short of time or resources. A benefit of semi-structured interviews is that the researcher has the ability to use follow-up questions to gain a deeper understanding of the topic (Israel, Eng & Schulz, & Parker, 2012). Yet, it can also be a disadvantage, as not all participants will be asked the same questions; making it difficult to draw comparisons across interviews (Mitchell & Jolley, 2012). Thus, researchers, through their additional questions, may influence the research outcomes. This method therefore requires a skilful researcher who is able to identify key words, ideas and themes and nonverbal cues (Klenke, 2008). Ultimately, semi-structured interviews were considered a good choice for exploring YWSW participation in HIV policies and programmes as it allowed for some structure in finding out about the topic but enough flexibility which may have helped participants to feel more comfortable during the interview process (Lincoln & Guba, 1985).

A small focus group discussion was also held with two CSO staff. The small number of participants is acknowledged as a limitation of the study. However, the discussion still provided opportunity to observe the interactive process between participants (Denzin & Lincoln, 2003), which is a key feature of focus groups.

4.4 Data collection

Participants

In the fieldwork stage five current YWSWs (see Table 1) were interviewed and a small focus group discussion was held with two staff from a Bangkok CSO, who had previously worked as sex workers. The YWSW participants were selected on the basis of age (20-24 years), requirement to be a woman, and self-identifying as a sex worker. Transgender women were not included in this study as the researcher felt that involving transgender women was beyond the scope of her expertise. The selected age range was based on “age of consent” in Thailand, which is 20 years of age, whilst still being in the age range of “youth” (UNESCO, 2014). The only selection criteria for the SWING staff were that they had been working with the organisation for at least one year so that they could be able to draw on their experiences of participation in HIV policies and programmes.

Table 1. *Young women sex worker participants*

Pseudonym	Type of establishment working from
Phara	Coyote bar
Jaidee	Bar
Tui	Bar
Malee	Bar
Amporn	Coyote bar

The two CSO staff members, who participated in the study, had also previously worked as sex workers, which was a criterion for their involvement in the research. In researching groups, such as sex workers, their involvement is sometimes challenging due to issues of mistrust and the illegal nature of the occupation. Sex worker collectives often play a crucial role in accessing this hard-to-reach population (Pyett, 2001). IPSR assisted in the recruitment of participants through SWING, which was key to the success of the study. SWING had previously been involved in other research projects conducted by IPSR and therefore a good relationship had already been developed between the two organisations. This helped to build the trust and rapport with participants in the current study.

Location of the research

The study was based in Bangkok, Thailand, one of the SWING locations, and also the home of IPSR. Sex work in Bangkok is concentrated within the Patpong, Soi Cowboy, and the Nana Entertainment Plaza areas. Soi Cowboy is known for its strip-clubs (where the primary role of the women is nude dancing and many establishments offer sexual services), and coyote bars (where the primary role of the women is clothed dancing, but many establishments offer sexual services). Sex work is negotiated at these sites but takes place off site. Strip clubs can also be found in Patpong, but this area is characterized mainly by coyote bars, other establishments which focus on the display of sex acts, and a few bars which provide oral sex. Nana Plaza is a three-story red light district that has predominantly coyote bars and some short-term motels on the top floor.

Through IPSR, I was provided with an office space and introduced to SWING who were key partners in my research. As presented in earlier chapters, SWING are a CSO who work closely with sex workers providing a range of services

and activities such as peer education, testing services, outreach, advocacy and a drop-in centre. Their staff and volunteers are predominantly sex workers, or have previously worked as sex workers in the areas of Patpong, Soi Cowboy or Nana Plaza. My decision to include SWING in my research was due to a recommendation made by IPSR. In addition, their experience in working with sex workers and involvement in national level health planning, meant that they would have good insight into the experience of YWSW participation. Through SWING, I was able to promote my research, recruit YWSWs for individual interviews and the two staff members of SWING who had been sex workers for the focus group discussion. The Empower Foundation, as mentioned in chapters two and three, are another CSO who work closely with YWSWs. However, due to IPSRs close relationship with SWING and their prior involvement in a number of evaluation projects; I decided to work with SWING as opposed to another CSO, like Empower.

Preparing for participant recruitment and interviews

Through IPSR I contracted a research assistant/translator to assist with translating during the interviews and transcribing the data afterwards. She had provided interpreter and transcription services for a number of research projects, one of which was with sex workers. Before recruiting participants, I met the director of SWING to discuss my research in detail and how I intended to recruit participants. I was then granted permission to hold a meeting at the SWING drop-in service. At the meeting, I talked about the research that I was planning to conduct, how long it would take, discussed issues of confidentiality and informed consent, what I intended to do with the results and what benefits there would be for participants. I explained that the interviews, with the help of the interpreter, would take a maximum of one hour and would involve a list of questions about participation in HIV policies and programmes. I mentioned that these interviews would be digitally audio recorded, transcribed at a later stage, and then participants would have the opportunity to review them for consistency. I left a drop-in box with expression-of-interest forms and information sheets next to it and advised I would return in one week to collect the forms and contact potential participants.

For the interviews, I had originally intended to recruit between four and six YWSWs, and in the end recruited five as one participant declined as she had to work. Both staff members had previously worked as sex workers. In their roles they

participated in peer education, outreach activities and referred sex workers to health-related services.

Conducting semi structured interviews

One-to-one semi-structured interviews were chosen as a data collection method, as it allows the researcher to explore answers in greater depth (Mitchell & Jolley, 2013). One-to-one semi-structured interviews allowed me the flexibility to explore individual's experiences in detail allowing each participant to have an equal amount of time. During each interview, I followed up on participant responses with further inquiry, for instance by asking them to provide examples. Due to the time it took the research assistant to translate and transcribe the interviews, my short time in Thailand and the busy work schedules of the YWSWs, I was unable to get participants to check the transcripts for accuracy. It is acknowledged that this is a limitation of this study. Some participants may have also felt self-conscious to provide feedback in front of their peers, fearing what they might think of them. As sex workers in Thailand are generally disempowered and lack trust, building a rapport was crucial to ensure the YWSWs' participation (Liamputtong & Ezzy, 2005). I therefore felt that this would be better achieved through one-to-one interviews as opposed to focus groups, which struggle to achieve the "collection and analysis of individual experiences" (Flick, 2014, p. 253). Due to competing work schedules I had to interview the women separately. It was also under the advice of the CSO and the interpreter that the interviews would be more appropriate given the women did not know each other and that might impact their willingness to share information.

All interviews were structured around these three questions:

- Do YWSWs think that participation in HIV policies and programmes is important and, if so, why?
- What is the extent of current participation of YWSWs in HIV policies and programmes?
- What are the barriers and future opportunities for YWSW participation?

In utilising a qualitative methodology, there is always the risk of influencing the findings through the participant-researcher interactions (Guba, & Lincoln, 1994). As such, before commencing the questions, I advised the participants that I did not have a particular view on the questions I was asking, that I was relying on them for their knowledge and experiences to inform the research. I summarised and reflected back their response to each question to ensure I had understood their response. Most participants could speak English. However to reduce risk of misinterpretation, each question was translated into Thai. Clarification of the questions was given where necessary. Once all the questions had been asked, I asked participants if they had anything else to comment on or any further questions. The types of questions asked of the SWING staff were similar but were extended to seek staff views on how they involve sex workers in their programmes, and how they themselves participate in HIV/AIDS policies and programmes now as CSO workers. On average, each interview took two hours, which was much longer than I had anticipated.

Data analysis

The data was analysed using thematic analysis via a manual coding system. Thematic analysis has been described as “a method for identifying, analysing and reporting patterns (themes) within data” (Braun & Clarke, 2006, p.79). A manual coding system was chosen over a computer based programme, such as NVivo, as these types of programmes can be time-consuming and may require the cost of additional software, hardware, training or technical support (Liamputtong & Ezzy, 2005).

My data analysis was based around Grbich’s (2013) process of thematic analysis:

- Familiarisation and transcription of data – After receiving the transcribed data from the translator, I compared the transcripts with the audio files to ensure consistency. I read each transcribed interview and recorded any initial ideas that I had around potential themes.
- Manual data coding – Using the manual coding example provided by Liamputtong and Ezzy (2005, p. 271) I printed the transcripts in landscape format with no margin, so that I could add columns to the right for ‘notes’ and the ‘final codes’. The notes column was useful to

highlight some of the key words or terms which were related to the themes.

- Reviewing and confirming themes – I then re-read the transcripts to ensure that the common themes identified were appropriate and made amendments where needed.

The coding of data involved relating themes to the participation framework discussed in Chapter 3, that is the Arnstein's 'Ladder of Citizen Participation' (Arnstein, 1969); a framework that has been adapted for work in different sectors including health. The framework, with the eight 'rungs' as a typology of participation commonly using themes of non-participation, tokenism and citizen power (Arnstein, 1969), is used as a means of interpreting and presenting the data in Chapter 5, the findings (Arnstein, 1969).

Ethical considerations

An application for ethics approval was submitted to AUTECH and was granted 15 October 2012 – reference number 12/269 (Appendix 1). Guided by the AUTECH principles, a number of strategies were employed to ensure that the study was conducted in an ethical manner. As the research concerns participants who are involved in an illegal occupation, there are additional ethical issues to consider (Liamputtong & Ezzy, 2005). These issues are captured in the following points:

- **Informed and voluntary consent:** The participants were all requested to sign the consent form and read the participant information sheet before their respective interview commenced. Both the consent form (Appendix 3) and the participant information sheet (Appendix 4) had been translated into Thai. All participants consented to participate in the study. After the participants signed the consent form they were asked whether they had any questions. Each interview was limited to two hours so that each participant had equal opportunity to participate. The focus group discussion took three hours. All interviews and the focus group discussion were recorded on a digital audio recorder for verbatim transcribing following the interview. All participants were asked permission to record the interviews and were told they could stop the interviews at any time if they felt uncomfortable. The same process took place for the focus group discussion.

- **Minimisation of risk:** I reminded the participants to not disclose anything of an illegal nature, and that if they had done so I would need to advise my supervisor. As conducting research with hard-to-reach populations, such as YSWs may put them at risk of unintentional danger (Liamputtong & Ezzy, 2005), I also reminded the participants that all identifying information would be removed, including places and work and names and location of workplaces.
- **Social and cultural sensitivity:** Prior to data collection I was introduced to IPSR and was offered support to carry out my research. The research was also discussed with the director of SWING. To ensure that the participants felt safe and confident to participate, I decided to conduct the research at an anonymous room at SWING. The interpreter had previously worked with the SWING so she had already developed a rapport with the staff. The days and times of the interviews were decided by the YSWs to ensure that the research did not impact their work schedule and their ability to earn a living. I briefly mentioned my research and work experience and what led me to research this area of work. I mentioned that I was of South-East Asian heritage and had visited Thailand the previous year on a study tour in the Isaan Region. I then invited the participants to briefly mention their backgrounds and the different settings they had worked in. I also encouraged them to ask questions along the way, as needed. Ethics approval was also granted by Mahidol University (Appendix 2) to ensure the research was ethically and culturally appropriate.
- **Confidentiality:** All interviews and the focus group discussion were conducted at SWING in a private room. Before the interviews commenced, I gave a summary of the research with particular focus on confidentiality, disclosure and how the findings would be used.

4.5 Conclusion

The participation of sex workers in HIV policies and programmes was explored through one-to-one semi structured interviews with five YSWs living and working in Bangkok, and a focus group discussion with two staff from a CSO who had previously worked as sex workers. Thematic analysis was used to identify key

emerging themes in the data. The stages in the analysis involved familiarisation and transcription of data, manual data coding by highlighting potential themes and patterns, and selection, review and confirmation of themes. In the next chapter, the findings of the research will be presented alongside Arnstein's (1969) Ladder of Citizen Participation. The themes that presented in the interviews and focus group discussions structure the findings accordingly: The first section discusses the importance of YWSW participation in HIV policies and programmes; the second section presents current participation; and the third section explores the barriers to participation and future opportunities. These three themes will be discussed using data from the interviews.

Chapter 5: Young women sex workers and participation in HIV policy/programmes in Bangkok

5.1 Introduction

The findings in this section are structured around the 3 research sub questions: the importance of participation to YSWs; current participation; and barriers and opportunities to participation. Within each section a discussion of the findings is provided in relation to the 3 research sub questions regarding participation. Themes that present in the data are derived from the semi-structured interviews and focus group discussion via thematic content analysis.

Quotes from the transcripts are presented below, along with pseudonyms to protect the identity of the YSWs. The findings are discussed with the ‘Ladder of Citizen Participation’ (Arnstein, 1969) framework in mind, as it forms the basis of much of the conceptual thinking regarding community participation within the literature.

5.2 Importance of participation

YSWs and the CSO staff were asked the question: “How important is it for YSWs to participate in the development of HIV policies and programmes?”

Recognition of the importance of participation demonstrates a level of community ownership over the problem (HIV); and for sex workers to participate in HIV services there must be a level of community ownership (Galavotti, 2012). All informants believed that the participation of YSWs in HIV policies and programmes was important for different reasons, for instance it could help to address stigma and improve access to testing services.

Yet, some YSWs interpreted participation to mean the gains made from the services, such as changing behaviour, rather than involvement in decision making, for instance engaging in peer education as a form of participation. This may reflect the lack of opportunity granted to YSWs in the decision making process, thus leading them to understand participation in terms of components of the service only, i.e. health education. This is in contrast to how participation is often contextualised in Thailand, as being a bottom-up approach, built on traditional values, local knowledge, trust and social cohesion (Funder, 2010). But it is not at odds with

biomedical services which tend to be expert and top-down structures (Bonita & Beaglehole, 2009) and historical approaches to Thai health-care provision which focus on patient compliance.

This could indicate a disconnect between how community participation is conceptualised by Thai people and the reality of participation, as a top-down approach led by those in power; typical of biomedical services globally.

The participation of YWSWs will help decision makers to understand HIV risk behaviour among this group, which would then lead to better targeted HIV programmes. One informant talked about the need to include young sex workers in the identification of some of the assumptions around sex work and HIV:

Phara said,

'If you separate those teenagers who are sex workers and those who are not, it seems that sex workers may be at risk. But they actually practice safe sex more than the regular teenagers because they all know that they are exposed to risks and what the risks are. There is also a requirement by the employers that they have to get themselves checked every how many months and also it's mandatory to use condoms with clients. While the regular teenagers, if they date someone, they go out with someone, they end up having sex; normally they do not protect themselves.

Sex workers use condoms with clients, not with their boyfriends. But they get themselves tested every month so they feel like whether or not they have sex with (using) condoms or without (using) condoms with their boyfriends but they know anyway that they're clean. (Phara, sex worker)

Consequently, YWSWs believe that, due to the fact that they are required to use condoms, they are at lower risk of HIV in comparison to youth who are not sex workers. No studies in Thailand to date compare condom use between sex workers and non-sex workers. Latimore et al. (2013) however found that young rural women in Thailand tend not to use condoms during sex with their casual partners. Some sex workers as referenced above do not use condoms with their boyfriends. These sex workers are at greater risk of HIV infection.

Three YWSWs talked about the need to encourage YWSWs participation due to their lack of HIV knowledge:

I feel there is a greater need for the younger ones than the older ones because the younger ones who have just entered the business may have less knowledge about HIV compared to those older ones. (Amporn, sex worker)

It would be good for young sex workers to participate especially when it comes to sex education. They may get education in schools but it's not in-depth enough, it's not detailed enough. I'm not studying anymore but I have had basic education and I feel like I

haven't received enough information on STI or HIV in school. In Thailand, from my experience, sex education is mainly how to prevent pregnancy but not so much on STIs. (Phara, sex worker)

It's important that young sex workers participate in the development of HIV policies and programmes because being a teenager, being young, is like you are growing up to be an adult. And there are still a lot of things to learn during teenage years. (Tui, sex worker)

These quotes demonstrate how the YWSWs interpreted participation as meaning participating in the objectives of the service, such as, changing behaviour. Participation has therefore been understood as a passive acceptance of programmes, in this case, condom use and education, and therefore akin to the Arnstein's forms of 'non-participation'. These forms of participation aim to 'cure' communities rather than address the underlying causes, which can be achieved through meaningful participation (Arnstein, 1969).

The findings indicate that there is a belief that increased participation by individuals in service goals and activities will result in programmes being more successful or accessible to sex workers.

Som said,

Because the young ones may not know yet what the problems are. It's important for sex workers to participate in such programs or policy development for example the treatment for STI or HIV/AIDs, the accessibility to the services. A lot of programmes that were funded by Global Fund for example were not very effective yet. Even though they include sex workers in the (XXX) programme but the power pretty much lies on the authorities and not on the sex workers.

YWSW participation is however dependent on the willingness of those in power to allow YWSW voices to be heard. The above quote demonstrates the lack of decision making power afforded to sex workers in developing HIV programmes. It is likely that this may have influenced the lack of success within the programmes that were supported by the Global Fund. Given YWSWs' vulnerability, and stigma by society, systems must be put in place to ensure decision making is accountable and transparent, i.e. the 'delegated power' rung of Arnstein's (1969) ladder, which forces decision-makers to consider community needs. This approach would help to ensure that services are better designed and suited to YWSWs.

Som talked about the importance of participation from the perspective of human rights :

Most of the time sex workers have problems with the police for example if they just stand out there on the streets, the police would arrest them; and if they carry condoms, the penalty will actually be more severe. And what they are trying to push forward is actually recognize sex workers as one of the occupations because if that is to be done then sex workers would receive benefit from the government like any other people in formal sector like social security, insurance etc. He said that the conflict is that the bar owners have the license to operate business legally but the people who work in the bars do not have any license or certificate to say that they are working there. And when they actually go out with clients, they are most of the time arrested by the police. There's no protection.

The quote shows that the CSO staff felt that participation was an important mechanism for advancing the rights of sex workers and advocating for legal reform to recognise sex work as a legitimate occupation. In addition to the references participants made to the importance of their participation, and a belief that their participation would result in improved HIV programmes and services, that would in turn encourage equality, YWSWs also mentioned their involvement in current decision making.

5.3 Current participation

The informants discussed the types of activities that they might be involved in. In addition to participation as individual changes to behaviour, other areas of participation they referred to were: peer education, and some participation on advisory groups and a police-targeted anti-stigma programme.

Peer education

As the term suggests, peer education involves typically an older peer or a peer who is more experienced in the subject matter, delivering education to a younger or less knowledgeable peer (UNICEF, 2012). The WHO (2013) argues that peer education programmes be well planned, offer adequate and ongoing training opportunities, involve educators who are committed to the needs of their peers, be responsive to local needs and offer peer educators the flexibility to adapt to these needs. Peer education should not only seek to increase capacity through increasing knowledge, but also involve its participants in the design, planning and evaluation of the programme.

In Thailand, HIV prevention activities are mostly conducted by NGOs and CSOs because of a lack of resources within the public health system. With no specific budgetary support from government to implement peer education for sex workers, these organisations rely on the Global Fund for some budgetary relief, however these funds are intended for the broader community (National AIDS Prevention and Alleviation Committee, 2012). The Thailand progress report for HIV does not report on peer education strategies (National AIDS Prevention and Alleviation Committee, 2012), despite their success among sex worker populations. This has important implications for the sustainability of peer education programmes, as the lack of resourcing for peer education may have a knock-on effect in terms of lack of participation (Cornish & Campbell, 2009). The development and improvement of most peer education programmes do not involve the input of participants. Instead, their participation is limited to receiving information on HIV, making it an example of Arnstein's (1969) notion of 'informing'. At the informing level, external agencies provide information to communities in regards to projects that they have already developed, despite their direct impact on the communities whom they are intended to target.

In the case of the YWSWs in Thailand, the findings showed that many YWSWs participate in peer education. The sex workers were asked about their involvement in HIV policies and programmes: "Have you been involved in the development of any HIV policies or programmes?" Some informants had been or were currently involved in a form of peer education, showing that opportunities for sex worker involvement do exist; others had taken part in outreach activities that involved condom distribution.

However, these are examples of opportunities, the actual participation in such opportunities is limited:

What I did was basically peer education, for example giving knowledge about the difference between AIDS and HIV, and how it is infected, and what kind of tests do they require. (Malee, sex worker)

I participated in activities at (identifiable information) and it's a kind of peer education thing. I give knowledge to other sex workers, my colleagues as well. For example, now there's condom for women. In order to double protect yourselves, maybe it's better to put that on as well because sometimes clients could be also tricky. I would put that on and then recommend other friends to put that on. And also make sure that the clients put their condoms on as well for double protection. (Phara, sex worker)

Sometimes we have a meeting and sometimes we suggest some ideas, for example how to get young sex workers to get themselves tested. For example, if you go to the bar at maybe 2 pm, then it's less likely that sex workers will come. (Phara, sex worker)

Beyond peer education, the data points to very limited opportunities currently available for YSWs to be able to provide input into HIV policies and programmes.

Advisory groups

The two CSO staff participants were based in one of Bangkok's busiest red-light districts. Kiet and Som had both previously worked as sex workers for a number of years so they were familiar with the industry and the political and social challenges that CSOs commonly face. As their participation in the development of HIV policies and programmes would provide a unique viewpoint, I asked the following question: "Have either of you been involved in the development of any HIV policies and programmes at the provincial and national levels?"

Kiet said,

We participate at the provincial level and attend conferences and seminars at the national level. We discuss survey results and propose some recommendations or things that need to be done at the next round of Global Fund, but we have withdrawn from the Global Fund already.

Som said,

Normally it's like they have the plan set already. Everything is set already. It's like "Do you agree with this?"

The participants mentioned their involvement in an advisory group which was set up to provide input into national HIV policy and programme planning. They also participated in advisory groups at the provincial (Bangkok) level. They expressed that they had withdrawn from the group, a factor that may indicate the lack of decision-making power they had within the group, further demonstrated by the last quote. The participants also discussed the membership of the advisory group and commented that high ranking police were encouraged to attend meetings, but often declined the invitation and instead would delegate the responsibility to a lower ranking officer. The participants commented on the difficulties they face in communicating with these officers, because they are often naive to the challenges that sex workers face in relation to HIV prevention.

In general, advisory groups are an example of what Arnstein (1969) refers to as 'placation'. At the placation rung of the ladder, community members are

representatives on high level boards or decision-making bodies. Community representatives are seen to be able to have their voices heard but in reality are forced to accept the proposals put forward by others with more power. This process is used as a way for governments to demonstrate that they have received wider input on the policy or plan, whilst still maintaining control over the main content and the end product (Arnstein, 1969). This demonstrates the tokenistic nature of such an approach which leaves communities feeling disempowered. The lack of commitment by high ranking police to attend meetings is another example of the tokenistic nature of the group; although even the involvement of lower ranking police may offer opportunities.

Anti-stigma programme with local police

I learned that a programme had been developed to address the negative attitudes of inexperienced police towards sex workers.

Kiet said,

The most important thing that needs to be done is to change people's attitude toward sex workers. But it's a huge thing to do.

By saying this Kiet shows that a change in attitude and a good understanding of stigma in the society is needed to even allow a space for YWSWs to participate. Kiet indicated that through helping others to understand the lives of YWSWs, attitudes of stigma could be addressed.

The informants explained that the programme involved police academy students coming to the CSO to learn about the lives of sex workers and the challenges they face, in the hope they will understand the workers better. As part of the programme, police were required to support the CSO on outreach activities and advise sex workers of their rights. This programme came out of a number of complaints which had been placed in the complaint drop-box at the CSO.

Som said,

We have a complaints box here at the office and people would just drop in the complaints and most of the complaints were related to the rights of the sex workers, they have been beaten up or they have gone out with clients but did not get their payments or something like that. So it started from those comments. We read all of those comments and discuss what need to be done.

The complaints box gives sex workers a chance to give their opinions about services and other issues they face on a day to day basis. These comments are taken seriously by the CSO as they have the ability to impact the CSO decisions around programme planning. This is an example of Arnstein's notion of 'consultation'. YWSW participation was limited to lodging complaints but they had no involvement in determining how to address or prioritise each complaint.

This programme is a good example of how marginalised groups can use innovative ways to improve the social environment that ultimately impacts their health and wellbeing. It also demonstrates an informal mechanism for sex workers to participate in the development of HIV policies and programmes. But merely consulting with people is not enough. YWSWs should be provided with an opportunity to shape the programmes that are created out of suggestions put forward in the complaints box.

5.4 Barriers

The informants identified many barriers to participation. These were categorised into (1) issues of fear, trust, stigma, power and the illegal nature of sex work, (2) issues of youth, inexperience and gender roles, (3) service barriers (4) and issues of voicelessness.

Issues of fear, trust, power and the illegal nature of sex work

Themes of fear, trust and power were presented frequently in the data and this was related to the authorities, like the police and local government, and their families. One informant talked about the barriers to sex workers being involved in the advisory group.

Kiet said,

The identity of themselves because they are new, they are inexperienced in the industry, it might be kind of difficult for them to be involved. The knowledge and the experiences—lack of knowledge and lack of experiences. We were actually finding those who would like to participate in (XXX) and we normally get rejection from the sex workers because they don't want people to know who they are and they are just basically afraid of the authority or that their family might find out about what they do for a living.

Som said,

They don't want people to know who they are and they are just basically afraid of the authority or that their family might find out what they do for a living.

My friends don't want to come and participate in activities or programmes relating to HIV because they are afraid that their names will come up. (Tui, sex worker)

If it's small activity like maybe having lunch together and then at the same time talk about sex education or STIs, how to protect ourselves or do it over coffee then it would be more tempting to participate. Because if it's a big campaign where everybody gathers, people see who we are. (Tui, sex worker)

The quotes above demonstrate that YWSW fear their families finding out about their sex worker status and this limits their willingness to be open about their situation. This finding is also supported in the IPSR (2013) study which found that many sex workers had not disclosed their occupation to their families. However, the findings show that participation can also take a more informal approach, which protects the anonymity of YWSWs.

Kiet talked about an experience at a meeting outside of Bangkok which demonstrated the lack of understanding that the police had:

I have attended a lot of meetings in many provinces but the worst has been to this one in the Southern province called Suratthani. Whatever I said the police would just have a come-back to me like "no, sex workers can't do this. Prostitution is illegal".

These responses demonstrate the powerless position of sex workers on the advisory group, the little value placed on their input and lack of respect they receive. Yet, despite these challenges, section 4.2 showed that CSOs are strongly committed to this participation agenda as a means to lobby the Thai government for the recognition of sex work as a legitimate occupation. This identifies a need for efforts which support greater understanding of the symbolic context of YWSWs lives, and the importance of YWSW participation for addressing HIV. The findings therefore demonstrate the challenges in applying a framework such as Arnstein's (1969) ladder, as it does not account for issues of fear, trust and the illegal nature of sex work, which are relevant for YWSW participation. In other words, the ladder does not account for marginalised groups within communities but assumes a degree of homogeneity within the community.

Som talked about the priorities of the advisory group, with injecting drugs users, migrant workers and students taking high priority. I asked "why do you feel they are higher priorities?"

Som said,

There are many obstacles in order to reach sex workers for example the law. We might have problems with police if we were going to do some interventions among sex workers.

Even though sex workers are a priority group for HIV in Thailand (IPSR, 2013), the illegal nature of sex work discourages the advisory group from prioritising programmes to suit their needs. Sex workers in Thailand have been found they frequently experience violence from police. This relates to arrests, sexual harassment, physical and verbal abuse, humiliation and threats to control and harm (Ratinthorn, Meleis & Sindhu, 2009). As stated earlier, there are currently two laws governing sex worker in Thailand, The Prevention and Suppression of Prostitution Act, B.E. 2539 (1996) and the Entertainment Places Act of 1966. The former, which prevents a person from soliciting sex or being linked to a “prostitution establishment”, may impact the extent to which or prevent sex workers from participating, and may be a key factor in the acts of corruption and violence that sex workers experience by the Thai police force. This further accentuates their position of disempowerment and has implications for meaningful participation in HIV policies and programmes. The illegal nature of their role in the community is another example of a significant barrier to participation which is neglected by participation theory like that of Arnstein (1969).

When asked about the barriers to YWSW participation in HIV policy and programme development, one informant referred to the political challenges that might arise:

If the government actually involves them in policy making, if the government launches any regulation that would help them, other people, the public may think that the government is trying to encourage prostitution. (Phara, sex worker)

Involving sex workers at all steps of the policy and programme development stage is important, so I wanted to find out whether they were involved in the advisory group’s plan from the beginning. It appears that there has been some success (if only minimal) in the adoption of sex worker suggested activities. I asked the following question: “You mentioned before that they often show you the plan and just ask if it’s okay, why is that? Why aren’t they involving sex workers from the beginning?”

Som said,

They actually involve NGOs in developing the plan, but the final version does not include any of their ideas. It's like you can say whatever you want, you can suggest whatever, but it might not end up in the plan. Because the plan of Bangkok has to actually go together with the national plan so there cannot be a lot of adjustment or changes.

This showed that the provincial plans were more of a sub-plan of the national one, rather than separate plans that reflected the individual needs of each province around HIV. It also showed that although sex workers are involved in consultation, their ideas are not reflected in the final plan, so their involvement is tokenistic in nature. Therefore, this is an example of Arnstein's (1969) 'consultation' rung, tokenistic consultation rather than genuine consultation. Similar to the placation level, at this level communities are manipulated into participating. This is often due to a lack of government funding or expertise. Further, communities are expected to implement these initiatives with no technical support from government.

The informants mentioned the current accountability measures put in place at the authority level. The current process allows all administration areas and NGOs to provide feedback, however this is a lengthy process which results in other voices not being heard.

Som said,

In Bangkok we have 50 administrative areas and they would all have suggestions. In addition, there would be comments and suggestions coming from over 100 NGOs. So when they are going to finalise the plan, they have to prioritise those comments and that pretty much takes up all of the plan.

This finding shows that in the development of HIV policy, participation can be challenging as it takes time to ensure all voices are heard. I wanted to know the level of participation among other sex workers so I asked the following question: "Do you know if any other people that work at NGOs or sex workers, have been involved in the advisory group or any other HIV policies or programmes?"

Som said,

I know a lot of them. It's always the same people in the meetings so we are familiar with each other. It will normally be 30-40 people in each meeting and the schedule is not fixed. There's no fixed time when we have the meeting, they will just call for a meeting, at least once a year.

The above quote demonstrates two issues. Meetings held by the group usually attract 30-40 people. In all groups, there will always be some who have more voice

or confidence than others. It is therefore ideal for groups to be smaller, to ensure that the ideas put forward are an accurate representation of the membership. Facilitation of the group is also more manageable in smaller groups. The size of the advocacy group may be a contributing factor to the challenges that the informants experience in relation to the group adopting their suggestions. The lack of organisation and frequency of meetings could also be having negative effects.

The findings showed that YWSWs relied on the CSO staff to act on their behalf as they believed they wouldn't be taken seriously. However, issues of trust, stigma and power prevented the CSO staff from any meaningful participation, thus further restricting the voice of individual YWSWs. This is typical of these kinds of forums which are often dominated and represented by those who have the most "voice", power, and status, which are usually adults and men (Conn, Modderman and Nayar, 2013). However, the work of Cornish, Campbell, Shukla and Banerji (2012) observe that "sex workers' experience could inform boardroom discussions. This will help to ensure that funding procedures become more responsive to local realities. In turn, sex workers' experience in the boardrooms would equip them with understanding of the funding environment to bring back to their projects". (p. 19)

YWSW fear of the power of the authorities and fear of disclosure of their occupation to their families are key themes in preventing meaningful participation in HIV policies and programmes. Past experiences with the authorities have also led to a lack of trust among sex workers to be involved in participation processes that involve the authorities. Sex workers also appear to have little power to participate in a meaningful way and have control over decision making, which as Arnstein (1969) suggests is the essence of 'genuine participation as opposed to the tokenistic partnership and 'consultation' approach.

Youth, inexperience and gender roles

In asking the sex workers about the barriers that exist, they talked about the status of women in Thai society and factors such as youth, experience and position.

The young sex workers are embarrassed to join this kind of activity. They're not aware of the risks given the job. (Jaidee, sex worker)

The main challenge for the young sex workers is that they have no knowledge of the business or anything related to the business, the risks or anything. They are as young as 14 years old. (Malee, sex worker)

Young sex workers are facing different problems like for example they do not know their rights and they have less bargaining power when it comes to negotiating the prices, the pay. If we include the young sex workers it will actually give significant impact and help them. (Kiet, CSO staff)

The first quotes may indicate that some YWSWs lack confidence and self-worth and do not understand the benefits of participation, demonstrating why it is of even greater importance for the younger sex worker. Their lack of experience in the sex industry may be a key reason why they may not understand the challenges that YWSWs face in regards to HIV prevention, their own rights or how HIV policies and programmes could better meet their needs. In other words, their frame of reference is different from more experience sex workers. Issues of voicelessness and wanting a voice also presenting in the findings.

Issues of voicelessness and wanting a voice

The findings indicated issues of voicelessness among the YWSWs. The CSO staff observed these challenges on the advisory group.

Kiet said,

They require two sex workers in each province to be on the committee (advisory group) and they're always accompanied by NGOs, because NGOs are actually those who speak for them because if they speak for themselves, no one will listen and they normally have problems with police.

NGOs that speak on behalf of their communities is an example of citizen control. Yet, as Arnstein (1969) argues, there is also risk of 'minority group hustlers' being just as exploitive as those in power. Therefore, there is a risk that the participation agenda is shaped by the needs of NGOs rather than the experiences, views and needs of YWSWs.

The participants talked about their power within the group. They commented on how they could have influence in the activities that were run at the provincial level, but they had little impact on HIV policies and programmes at the national level. Also, each provincial group was run differently and the participants felt that it was harder in Bangkok to have influence over HIV policies and programmes.

Kiet said,

Our voices are not heard yet. Even though we are there but it seems like our power is less than other members. Maybe one of the reasons is because sex workers are not legal at the moment so it is hard to achieve that.

Som said,

It's very difficult to have our voice heard. For example, we would have a meeting to develop a brochure to promote the programme, but they had already produced the brochure...I feel I cannot really say what I want in those meetings.

The findings show that the CSO staff felt voiceless to have any real impact within the group. This reinforces the tokenistic nature of their participation. Yet, their meaningful participation would increase the likelihood of HIV policies and programmes meeting YWSW needs. This is another example of the 'informing' rung of Arnstein's (1969) ladder. Despite minimal opportunity to present their voice, CSO staff demonstrate a desire to take control and voice their opinion. This is promising for YWSW participation and presents an opportunity for policy makers and programme developers to target their efforts. As such it is also a form of manipulation and is an approach which is tokenistic.

Stigma and negative attitudes towards YWSWs also contribute to the problem of voicelessness:

Maybe it's because most of the people do not approve of me as a prostitute, as a sex worker, mainly because of my occupation. (Amporn, sex worker)

The stigmatization and the attitude of the people in general toward sex worker, that it's a bad thing. And if the government actually involve them in policy making, if the government launches any regulation that would have them, other people, the public may think that the government is trying to encourage prostitution. (Phara, sex worker)

The findings show that sex workers input into decision making processes is not valued, despite sex workers demonstrating a desire for greater involvement and literature which shows the benefits of sex worker participation (Chakravarthy, Joseph, Pelto, Kovvali, 2012; Cornish & Campbell, 2009). This shows that even at the highest rungs of Arnstein's ladder, such as the 'partnership' level, the Thai government may still be wary to hear the voices of YWSWs for fear of poor public sentiment. These findings further emphasise the need for efforts that address community stigma. Participation approaches that take the form of 'citizen control', such as the 'social movements model' of participation discussed in chapter 3, have been successful in addressing community stigma Campbell, Cornish, Gibbs, & Scott, 2010). Such an approach should be explored for YWSW participation in Thailand.

5.5 Opportunities for future participation

Ultimately, the goal of greater sex worker participation is the reduction of HIV and improved health outcomes for sex workers. To gain a deeper understanding of this, the informants were asked: “Do you think that greater participation of sex workers in HIV policies and programmes will improve the lives of sex workers?”

Som said,

Definitely, because it will be one of the channels to express what is needed to be done in order to help improve their lives.

If there were to be any opportunity for young sex workers to participate in any programme development, I feel that that all sex workers would participate. For example, tomorrow night there will be this parade called “Nana safe zone”. Nana is an area along Sukhumvit Road and it’s actually very close to Soi Cowboy. There’s going to be a parade and all female sex workers will be participating. (Malee, sex worker)

A CSO staff member felt that increased participation would be beneficial as it would provide YWSWs with an opportunity to voice their needs. The findings also showed that YWSWs were interested in participating and it was evident that some were already participating in programmes such as peer education. Yet, there was no evidence of YWSW participation in the development of programmes. However, if given this opportunity, due to issues of police violence, stigma and trust, it is likely that YWSWs would not feel safe to engage in any meaningful dialogue with the authorities.

Phara said,

It would improve the lives of sex workers. If you are going to talk to the mama san, she’s the owner of the place so there may be some conflict of interests. But if we are to do some activities, the time to carry out the activities or discussion with the mama san and the sex workers, it should be may be 4-6pm at the establishment. (Phara, sex worker)

This quote demonstrates that although YWSWs feel that participation would improve YWSWs lives, this participation would need to be negotiated with the Mama San (the manager of the venue). This is an example of the power conflicts that exist within communities; and is an issue for participation as these people are often the ‘gate-keepers’ to the participation of vulnerable groups such as YWSWs.

YWSWs suggestions to improve prevention activities such as peer education indicate sex worker capacity to contribute to HIV policy and programme discussions.

If the peer education activity was carried out for a long time then it would eventually reduce HIV/AIDs. (Phara, sex worker)

The current activity is not sufficient. Giving knowledge and giving condoms are not enough. There has to be some more activities but I can't think of one at the moment. But I strongly feel that it's not enough. (Malee, sex worker)

YWSW capacity is also indicated by the acknowledgement that peer education should fit within a broader HIV prevention framework. This demonstrates that YWSWs are aware of what needs to be done to address HIV and provides a strong case for their participation.

5.6 Conclusion

This chapter discussed the findings of the research alongside Arnstein's Ladder of Citizen Participation (Arnstein, 1969). The research questions that guided this study were used to present the findings under themes of importance of participation, current participation and barriers and future opportunities. The CSO staff and the sex workers felt it was important that sex workers participated in HIV policies and programmes.

Yet, where opportunities to participate are available, issues of fear, trust and power have been identified as factors preventing sex workers from participating. The next chapter will discuss these findings in relation to HIV policy and programmes in Thailand using Arnstein's (1969) Ladder of Citizen Participation.

Chapter 6: Implications of the study of participation of young sex workers in Thai HIV policy and programmes

6.1 Introduction

This chapter will discuss the findings along-side the eight levels of Arnstein's (1969) Ladder of Citizen Participation, and consider some strategies for greater YSW participation. The research question of this study was: "To what extent do young sex workers participate in HIV policy and programmes in Thailand?" The objectives of the research were to determine the current situation of participation, barriers to participation, and opportunities for increased participation. The Ladder of Citizen Participation was adopted for use in this study as it provides a lens to assess community participation. However, as was explained in Chapter 3, current literature on community participation is weak when it comes to providing theory for marginalised groups, such as sex workers or youth.

6.2 Ladder of Citizen Participation

Therapy and manipulation

YSWs have very little involvement in the decision making process around HIV policy and programmes in Thailand. It is clear that decision makers are instead made up of donors (The Global Fund), government and key Thai providers such as CSOs and NGOs. Indeed, given the competing needs of this group of actors, any kind of community participation may be considered a challenge. This is in line with the findings of the IPSR study which found no involvement of FSWs in the planning or evaluation of HIV policies and programmes (IPSR, 2013). The present situation in Thailand is reflected in the bottom rungs of Arnstein's ladder (1969), which Arnstein states constitutes a form of "non-participation, as observed in the therapy and manipulation rungs. At the therapy level, communities are not afforded any formal opportunity to participate in the development of HIV policies and programmes and governments display no regard for the welfare of these communities. The aim of such power holders is to 'cure' communities of their illness, rather than identifying the underlying cause of the issue. Often projects labelled as being for the interest of the community are in fact hiding ulterior motives and those in authority often manipulate the participation of vulnerable groups to their favour.

At the manipulation level, community participation is no more than a rubber stamp exercise in which some researchers believe community input to be a token gesture made to pacify communities or to satisfy funding requirements (Minkler, 2012; Weil & Romocki, 2006). Community representatives may be placed on advisory boards or committees that appear at face value, to be community driven. Instead such mechanisms are used as an instrument to educate communities as a means of engineering their support. It is evident, even at this level of non-participation, that it is unlikely that YWSW will be considered suitably qualified to participate, a factor that appears to be demonstrated in this study.

This level of participation differs from the placation level discussed below as communities involved in this kind of participation are made to believe that the government's goals are their own. In these cases community members may feel their role is primarily decorative and that those in power who seek their feedback will ultimately ignore their input (Minkler, 2012). This is contrary to the Manipulation level, where communities are openly forced into accepting the government's views. For the case of Thai providers, there is also risk that vulnerable groups could be exploited in order to push particular agendas and manipulate these groups into thinking that they have been provided a real opportunity to voice their needs. Traditional cultural pressures that are placed on Thais to reciprocate good will and customs of "phu noi tong kaow rob phu-yai" (little people should respect important people) and "kraenjai" (deference to people who have power or authority) (UNDP, 2013) may also provide the basis for YWSW involvement in such activities, even if there is nothing for them to gain.

Historically, Thai women do not participate in health care planning despite the benefits (Chunuan Vanaleesin Morkruengsai Thitimapong, 2007). It was generally believed by Thai people that a good outcome would result if they relied on the hierarchically organised health-care system, which assumed that professional knowledge was far superior to their own lived experiences. Similar to western approaches to healthcare planning Thailand's Guidance Cooperation Model continues to discourage independent thought and meaningful participation. This model asserts that patients should 'cooperate' with the professional's recommendation, due to their position of lesser power (Chunuan, Vanaleesin, Morkruengsai & Thitimapong, 2007). This assumption of 'doctor knows best' may

indicate how Thai women conceptualize participation in health care planning, and be a reason as to why YWSWs, in this study, interpreted participation as behaviour change.

Similarly, the findings of this study showed that funding priorities for HIV in Thailand are determined by donors and the Thai government, which are narrowly focused on the general population. It is likely for this reason that the Thai government perceives little value in engaging sex workers meaningfully in HIV policy and programme development and why, in principal, they support prevention activities that are typically top down orientated such as peer education, pamphlets on health messaging, and condom outreach.

The literature presented multiple and compounding factors that impact the ability of YWSW to participate in HIV prevention such as trafficking, violence, the legal system, the police and stigma (Odinokova, Rusakova, Urada, Silverman, & Raj, 2014; Scorgie, Vasey, Harper, Richter, Nare, Maseko, & Chersich, 2013). The limited opportunities afforded to YWSWs to communicate their experiences of how these factors hinder participation results in a lack of understanding amongst policy makers and programme developers. Even when policy makers and programme developers are aware of these factors, pragmatic norms of providing narrowly focused services prevent them from truly connecting with YWSWs getting involved in such social determinants as legal issues, police and community attitudes. This culture of non-participation will ensure that HIV programmes will continue to take traditional approaches and not address the underlying barriers to HIV prevention. There were no examples of the therapy rung of Arnstein's Ladder of Participation, which is characterised by those in power engaging with communities as a means to cure them (Arnstein, 1969).

While no specific examples of manipulation were present in the findings, the advisory group example demonstrated that the CSO involvement was no more than a rubber-stamping meaningless exercise.

Informing

Arnstein (1969) asserts that informing people of their rights, responsibilities and options can be the most important step in legitimate community participation, yet often it involves a one-way flow of information, with no opportunity for people

to provide input or build their capacity through exchanging, discussing and implementing their ideas, which is the nature of participation, as described by Freire (2000).

Informing as participation was a feature in this study, with health messages, through leaflets and peer education, being part of HIV programmes. At the informing level, external agencies provide information to communities in regards to projects that they have already developed, despite their direct impact on the communities whom they target. This level of participation is similar to the placation level, whereby people are placed on advisory boards only to be forced to accept the decisions of others. This was evident in the findings of the focus group discussion. The CSO workers commented that a meeting was held to develop a pamphlet, but when they arrived at the meeting they were informed that the pamphlet had already been developed. Another aspect of this level of the ladder is that it does not allow a channel for feedback and there is no power for negotiation, which was the case for the CSO workers in the pamphlet example.

The sex workers frequently referred to their involvement in peer education. This was typically part of an outreach effort in and around sex worker establishments. The contextual location of the peer education imposed limitations on the delivery of the sessions which were described as being one-off, informal and not well planned. These findings support the literature which observes that peer education, as a strategy for HIV prevention, has historically not been able to achieve strong outcomes (as cited in Cornish & Campbell, 2009, p. 2). While there was some opportunity for peer educators to inform the delivery of programmes (i.e. how best to reach sex workers), those YWSWs receiving the peer education had no influence over the design and implementation of these programmes. This finding is also consistent with the IPSR study which found that peer educators were only involved in their assigned duties, but had no involvement in programme design, planning or evaluation (IPSR, 2013).

Yet peer education, should not be disregarded. It may provide an opportunity for enhanced empowerment, self-worth, social cohesion among sex workers, and leadership skills, due to the peer educators lived experiences. To ensure that peer education can provide the opportunity for assured benefits, peer education programmes for YWSWs should be well planned, offer adequate and ongoing

training opportunities, involve educators who are committed to the needs of their peers, be responsive to local needs and offer peer educators the flexibility to adapt to these needs (WHO, 2013). Peer education programmes which are well-planned must also be evaluated and researched, as it is this evidence that supports policy commitments by government. It is likely that the importance of peer education as a participatory approach for sex workers is not well understood or developed in Thailand and in other contexts. This is demonstrated through the lack of mention in Thailand's National Composite Policy Index (NCPI) report to UNAIDS (UNAIDS, 2012), which provides progress on national HIV policies and strategies. A possible explanation for this lack of reporting could be due to factors such as funding, i.e. if certain programmes are not funded by donor agencies, they may not be highlighted in donor reports. Therefore, CSOs and other organisations working with sex workers must identify alternative avenues for reporting the benefits and successes of peer education programmes in such a way that they link them to wider capacity building and participation goals.

Consultation

Similar to the placation level, consultation with communities is often about being manipulated into participating and their involvement is often of a tokenistic nature. This is predominantly due to a lack of will, resourcing and expertise. Communities are expected to implement these initiatives with no technical support from government. The findings showed the challenges of incorporating multiple voices into HIV policy development. The CSO staff commented that meetings were held in each province of Thailand to provide input into national HIV plans. For the case of Bangkok, there were 50 administrative areas and over 100 NGOs who were interested in providing input. The findings indicated that there was no support from government to assist in the coordination of the consultation process and therefore most of the time spent on developing the plan was allocated to collecting stakeholder input, rather than supporting a dialogue. This example of participation demonstrates the inability of the 'consultation' approach to meet the needs of YWSWs. The lack of planning into the consultation process demonstrates the tokenistic nature of this exercise and shows how government were merely trying to appear that consideration had been given to the needs of sex workers. However government must realise that how they consult with YWSWs has implications for HIV policy and programme development. Approaches that do not intentionally capture the views of YWSWs

(such as the example presented above) will not speak to the real issues at hand, such as how to reach those sex workers who are disproportionately affected by HIV. YWSW participation must be built upon thorough planning and provide a ‘space’ that encourages open and meaningful dialogue, rather than consultation aimed to only meet the needs of decision-makers

Placation

As defined and discussed in Chapter 3 placation is where community representatives are seen to be able to have their voices heard but in reality are forced to accept the proposals put forward by others with more power. This process is used as a way for governments to demonstrate that they have received wider input on a policy or plan, whilst still maintaining control over the main content and the end product (Arnstein, 1969). As such, this process is a tokenistic exercise and leaves communities feeling disempowered.

An example in the findings that relate to this level of participation is in regards to the CSOs involvement in the advisory group. The advisory group was a national group established to develop policies and plans related to HIV. Each person was invited into the group to provide expert advice and guidance in relation to the community or organisation they represented. The CSO staff explained how they provided consultation on the national plan and a pamphlet. With regards to the national plan, they were only asked to provide feedback once it was developed and even then their feedback was not incorporated. The tokenistic nature of advisory groups was also experienced by IDUs in Thailand who participated in a drug trial to prevent HIV infection. A letter received by researchers from several groups of community activists representing those participating in the trial stated “the community should be treated as equal partners...with genuine community involvement. We insist on true involve in the process...and will not accept a token role on a community advisory board that is established after the protocol” (Weil & Romocki, 2006). Vulnerable groups such as YWSWs and IDUs experience community stigma. This may be a reason as to why both these groups experience challenges in having their voices heard within these forums. As Heritage and Dooris (2009) concur, these findings demonstrate a form of passive participation, indicating a lack of trust in community ability which often forms the basis of typical consultative processes.

Having an advisory group that includes the authorities may not be appropriate given police attitudes towards sex workers and the fear sex workers have in voicing their opinions. An example of police attitudes towards sex workers was demonstrated at a meeting where a police officer stated “no, sex workers can’t do this. Prostitution is illegal”. Given these negative attitudes towards sex workers, it is likely that they did not feel comfortable in voicing their opinions for fear of ‘backlash’ from police. The advisory group increased the vulnerability of sex workers by not providing a strategy to protect sex workers against police abuse. This supports the call for participatory approaches that are driven by sex workers, such as a group made up of only sex workers from a particular type of work location. This was also suggested by a CSO staff member in the findings, but it was due to a lack of leadership that it had not commenced. Such a group would be a useful mechanism to provide direct input toward all aspects of HIV policy or programme development or review the quality of existing testing services. It could also help to focus the policy discussion, towards one which is more aligned to YWSW needs and addresses not only the structural barriers surrounding HIV but also the social barriers, such as violence or stigma. The members of the group could also potentially play a role in the development of research and evidence on these issues that provide the basis for HIV policy. For instance, they could partner with government or donors to help guide the research methodology and methods to ensure that they are appropriate for YWSW needs. They could even carry out research or recruit other YWSWs to work as researchers, which may be appropriate given the difficulties ‘outsiders’ face in researching sex workers in Thailand, due to traditional Thai customs which are deeply embedded in Thai culture (Holmes & Tangtontavy, 1999).

To ensure that these groups are accountable and meeting the needs of all sex workers, they must have the capacity to meet regularly, report on their discussions and actions, have good leadership, be monitored by management, include mechanisms for resolving disagreement, and provide feedback channels to YWSWs and other sex workers whom they are representing. This type of approach can also involve YWSW groups partnering with government or donor groups. This leads onto the next rung of the ladder, the partnership level.

Partnership

Partnership in Arnstein's framework is the idea that community and policy makers or planners work together towards a common goal (see Chapter 3). There is a commitment to shared planning and decision making and mechanisms for conflict resolution, with formal structures set up to achieve this. At this level there is a degree of shared power, although not necessarily equal, with more powerful stakeholders no doubt having a bigger say.

The literature discussed in Chapter 3 pointed to Thai models of participation, including Community Capacity Building (CCB) which is based around a bottom-up or community determined process with the aim of building community empowerment and competency, as opposed to a top-down externally-based approach where those in power impose their own agendas (Raeburn, Akerman, Chuengsatiansup, Mejia, Oladepo, 2006). The rural community development programme in Khon Kaen province Thailand was a dramatic and successful historical example of CCB in action, and shows that effective partnerships with NGOs and government organisations can be possible given the right conditions (Raeburn, Akerman, Chuengsatiansup, Mejia, Oladepo, 2006). This example demonstrates that where there is political will and an absence of barriers to prevent participation such as the illegal nature of sex work, large scale participation can be carried out to meet local needs. The projects ability to foster participation may have also been due to the influence of powerful actors like scholars and doctors who were focused on meeting the needs of the community.

In this study, while there were examples of sex workers and government working together (such as the 100% condom programme), there is no evidence of government sharing power or decision making responsibility with sex workers. The sex workers did however make reference to a programme developed to improve police attitude towards sex workers. While it was not clear how the power was shared between the sex workers and the police, the programme was no doubt a success in helping to change police attitudes. At the partnership level, participation is effective when the community base is well organised. As the CSO is a well-established organisation, operating with the support of their volunteers, it is likely this was a key contributing factor to the success of the programme. This example demonstrates that a degree of partnership is possible and presents an opportunity for

sex workers to address other issues. For instance, sex worker collectives could partner with local health services to address the barriers mentioned in the findings that prevent YWSW access, such as stigma, anonymity and cost. YWSW participation that adopts a ‘partnership’ approach may also help sex workers to understand how to work more effectively with other powerful groups such as politicians or prominent business people, and identify what influences them. This leads onto the next rung of the ladder, known as delegated power.

Delegated power

Delegated power is a further step towards community participation with the community having greater control over the participation process than the power holders. It can involve community members holding the majority of seats on decision making bodies, where they have specified powers. At this level, power holders are forced into considering community needs. There was no evidence of participation at this level within the findings of this research. Indeed, given the marginal position of YWSWs it would be surprising to find such an example of community power. There are a number of factors which make it particularly difficult for YWSWs to experience delegated power – these are stigma and a perception that YWSWs do not have the capacity to make well-informed decisions.

There is a need for HIV policy makers and programme developers to be better informed about the barriers and opportunities to community participation. They need to have a better understanding of the roles that sex workers can play, and how their policies and programmes will benefit from greater participation.

In Thailand, some progress has been made to increase public participation in health care delivery via the National Health Assembly (Rasanathan, Posayanonda, Birmingham, & Tangcharoensathien, 2012) however; there is no clear strategy for ensuring the views of marginalised groups such as YWSWs. As Choguill (1996) suggests, the ability for communities to participate in decision making processes is dependent on the government’s attitude towards that community. The findings showed that factors such as the illegal nature of sex work in Thailand contribute to the willingness of power holders such as the police to involve sex workers in high-level decision-making. This further highlights the importance of programmes such as the police programme mentioned above in improving social attitudes towards sex workers. Not only will such programmes designed to raise awareness and change

attitudes help to reduce the factors, such as violence, which place young women sex workers at risk of HIV, they will also help to address challenges to participation. This will increase the likelihood of decision makers supporting participatory approaches which promote delegated power.

Power can also be delegated to particular groups with the level of power being predetermined via a contract (Arnstein, 1969). The desire to have a group made up of sex workers to feed into HIV policy and programme development was indicated in the findings by one of the CSO staff. However, a barrier to this being initiated thus far was the willingness of someone to lead this group. The absence of a leader to guide a sex worker group which feeds into planning processes could be a result of past experiences that have disempowered sex workers. A lack of adequate funding to support this group may also be a factor preventing its development. If such a mechanism was funded by Government, and formalised through a negotiated contract, leaders within the sex worker community may be more receptive to this approach.

YWSW participation can also be ‘delegated’ to aspects of health service delivery. For instance, through adequate training and remuneration, YWSWs can be involved in clinic management. This may also be a more appropriate approach to accessing and increasing coverage rates of those sex workers who are most hardest-to-reach. And through YWSW participation in health service delivery, they will be better placed to provide input into aspects of HIV policy.

Citizen control

Citizen control is where communities on their own initiative and resourcing, work to address their own priorities. It does not necessarily mean that communities are without support from government, as this could also involve governments allocating some resources.

Sex worker collectives like ‘SWING’ or ‘Empower’ are examples of citizen control as the power lies with the sex worker community and they have total control over setting their priorities. With this in mind, sex worker collectives may be a more realistic approach to increasing the participation of YWSWs within the current Thailand situation. Sex worker collectives are best placed to communicate with sex workers to voice their needs and identify emerging issues in the various sex worker

communities (WHO, 2013). As a group, sex workers are stronger, more vocal and more likely to hold power. While there is an acknowledgement that sex workers are not a homogenous group, there is opportunity for sex worker collectives to come together and provide a joint voice. Once sex worker collectives are more empowered and ‘vocal’, there will be greater expectations and pressure on government to share resources and power. They will also have access to a greater number of networks and people, including government allies, who might share the same vision and commitment to addressing sex worker needs (WHO, 2013). These supporters will be key to ensuring the voices of YWSWs are heard

Sex worker collectives will also be better placed to lobby and advocate for policy and legal reforms, not just with central government, but also at the local level and with local providers such as health facilities who provide services to YWSW. Greater solidarity amongst sex worker collectives can also increase access to a greater range of resources and skills, which will help to ensure the sustainability of programmes such as peer education (WHO, 2013). Governments may still play a role in ensuring the sustainability of sex worker collective driven programmes and the collectives themselves, by funding opportunities to build capacity. For instance, training that improves knowledge and skills around financial and project planning, research and evaluation and resource mobilization (WHO, 2013). Improved capacity will help to provide sex workers collectives to attract funding which will help to ensure that HIV programmes are well planned and comprehensive and they have the human resources to deliver programmes. HIV programmes may in turn produce greater results, which will help to attract greater donor and government funding opportunities, as investing in sex worker collective programmes will be seen as a worth-while investment. Sex worker collectives are well placed to encourage the participation of YWSWs in HIV policy and programme development. For instance, the ‘safe space’ offered within their organizations can be used to deliver workshops on HIV policy or programme planning. The governance bodies of sex worker collectives can also provide an opportunity for YWSW participation and will help to ensure that their needs are prioritised, thus helping to build self-worth, leadership skills and confidence. The literature presented an approach well known in Thailand, used to address complex social and public health problems. The model, known as the “Triangle that moves the mountain” (Wasi, 2000), is focused on three areas: the creation of relevant knowledge, social involvement and political involvement. These

three areas may provide a focus for the sex worker collective agenda to address HIV among YWSWs.

6.3 Conclusion

This chapter compared and discussed sex worker participation in HIV policies and programmes in relation to Arnstein's Ladder and provided some suggestions for how greater participation by YWSWs could be achieved.

This study has shown that YWSW participation is limited and far from Arnstein's notion of genuine citizen control. The lack of priority given to addressing YWSW needs in regards to HIV prevention offers little opportunity for their involvement in decision making in regards to HIV policy development. Where opportunities to participate are afforded to sex workers, they are tokenistic, do not encourage open dialogue and do not value sex worker participation. In addition to poor opportunity for participation, the factors that put YWSWs at risk of HIV such as stigma, violence and the illegal nature of sex work also prevent their participation.

The example of the anti-stigma programme with police show that YWSWs have the capacity to develop programmes that meet sex worker needs and address challenging social issues, with little support from government. Yet, it is encouraging to note that young women sex workers who participated in the research demonstrated a desire for greater involvement in HIV policies and programmes in a meaningful way.

6.4 Recommendations

YWSW collectives provide the current platform for YWSW participation. These efforts could be improved so that YWSWs are included in the design, planning and evaluation of programmes such as peer education and those which address the social barriers to HIV prevention such as stigma, violence and gender inequality. Due to the diversity of sex work in Thailand, there is opportunity to better meet the needs of different types of sex workers. This could be achieved by forming advisory groups made up of sex workers from specific work locations. Such groups would be a useful mechanism to provide direct input toward all aspects of HIV policy or programme development or review the quality of existing testing services. It could also help to focus the policy discussion, towards one which is more aligned to YWSW needs and addresses not only the structural barriers surrounding HIV but also the social barriers, such as violence or stigma. The members of the group could also potentially play a role in the development of research and evidence on these issues that provide the basis for HIV policy. For instance, they could partner with government or donors to help guide the research methodology and methods to ensure that they are appropriate for YWSW needs. They could even carry out research or recruit other YWSWs to work as researchers, which may be appropriate given the difficulties ‘outsiders’ face in researching sex workers in Thailand.

Opportunities for participation, even within sex worker collectives should be focused on creating a positive experiences which can also demonstrate that YWSW participation can lead to creating positive change. If this can be achieved, it is likely that other YWSWs would be more receptive to opportunities for participation. Sex worker collectives should also be encouraged to partner with external agencies such as local health services to address the barriers that prevent YWSW access to testing services, such as stigma, anonymity and cost. The Thai government and donors can play a role in supporting participation of sex worker collectives and their members by funding opportunities that build capacity, skill development and empowerment, which have proven to be key factors in improving health.

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Appendices

Appendix 1. AUTECH ethics approval letter

Appendix 2. IPSR ethics approval letter

Appendix 3. Consent form

Appendix 4. Participant information sheet

Appendix 5. Interview questions

Appendix 1: AUTECH Letter

School of Public Health and Psychosocial Studies
AUT University
Room AR324
90 Akoranga Drive Northcote 0627
Auckland 1142

19 November 2012

Dr. Rosemary Godbold
Auckland University of Technology Ethics Committee
AUT University
Room WA505E, Level 5, WA Building
55 Wellesley Street East
Private Bag 92006
Auckland 1010

Dear Dr. Godbold,

Subject: Ethics Application - 12/269 Young sex workers participation in HIV/AIDS policies and programmes in Thailand.

Thank you for your letter dated 15 October 2012. Please see below the responses to the conditions required, as stated in your letter, for final ethics approval.

Provision of more information in section G.2 of the application detailing how the consent forms will be handled in a confidential way at SWING

The consent forms will be given to those participants who are literate by the researcher and signed directly prior to the interviews being conducted. Once an interview concludes, the researcher will store the consent form in a locked filing cabinet of the Thai supervisor's office at Mahidol University.

Clarification and justification as to why only women are being interviewed

Young women sex workers in Thailand were identified in a literature review by the researcher as a most at-risk group for HIV. Furthermore, it would not be culturally appropriate for the researcher to interview men.

Clarification as to how participants who are illiterate will express their interest and give consent to participate in the research. AUTECH suggests consent is obtained by the researcher at the time of the interview and prefers that this be obtained verbally and tape recorded if participants cannot sign their name on the Consent Form

A meeting will be held at SWING to generate interest in the study; this will ensure potential illiterate participants are not excluded. Those who are interested in participating will give verbal consent and this will be recorded by dictaphone. Each participant's verbal consent will be recorded on a separate tape, and these will be stored along with the consent forms at Mahidol University (in the location mentioned above).

Clarification of how participants who cannot read will be assisted to review their transcripts

The translator will be assisting the researcher when the participants (literate or not) review their transcripts.

Provision of written and verbal advice to participants not to disclose any illegal activity and inclusion of a protocol outlining how the researcher will manage the disclosure of any illegal activities

The following sentence has been included in the Participant Information Sheet – “If you chose to participate, we ask that you do not disclose anything of an illegal nature in the interview. If this occurs, I will need to inform my supervisor”. Participants who agree to participate will be reminded of this at the interview. The Safety Protocol has also been updated, and includes the following sentence – “Any disclosure of information from participants regarding illegal activities must be referred to Dr. Miller”.

Reconsideration of interview question 4 so that confidential information about other sex workers not participating in the research is not divulged. AUTECH suggests including something like ‘Without giving specific details...’ to ensure it remains a general question rather than one seeking details of other people and locations that could be identifying

Question four has been amended to read – “Without giving specific details, such as names or places of work, do you know of other sex workers who have been involved in the development of policies or programmes?”

Amendment of the Information Sheet as follows:

a. In the section on costs establish an amount or limit that you will reimburse and advise participants of this;

b. In the section on ‘What opportunity...; insertion of missing word between ‘invited’ and ‘to’;

The section relating to costs has been changed to read – “There are no financial costs to you. If you require travel costs reimbursed, please let me know at the information meeting. In total, a maximum of 200 baht can be given”. No word is missing between the words ‘invited’ and ‘to’.

Provision of the translations of the Consent Form and the Information Sheet.

A professional translator/transcriber, Reena Tadee, has been contracted to assist the researcher. Reena has come highly recommended from Mahidol University and has provided services for many research projects. She will be contracted to translate the consent form and participant information sheet, translate at meetings with interviews and transcribe the data. A Thai professor will check over the consent form and participant information sheet.

I trust that the responses and amendments mentioned above are sufficient to meet final ethics approval. Please don’t hesitate to contact me for further clarification or to discuss anything mentioned above.

Kind regards

Dr. Cath Conn
Senior Lecturer and Programme Leader Postgraduate Public Health
+64 9 921 9999 x 7407
cath.conn@aut.ac.nz

Appendix 2: IPSR ethics approval letter



August 10, 2012

Dear AUT Ethics Committee,

I am Foreign Expert (Assistant Professor) at the Institute for Population and Social Research (IPSR) at Mahidol University in Thailand. I am writing this letter in support of Kristel Modderman's ethics application for her Master's Research entitled "Young Sex Worker Participation in HIV/AIDS Policy and Programmes in Thailand". Kristel's proposed research will be carried out in partnership with Mahidol University and will be part of a broader research assessment, "An Evaluation of the National HIV Prevention Program among Most at Risk Populations, Prisoners and Migrant Workers", currently being carried out by IPSR faculty.

We are pleased to have Kristel join us at IPSR from December 2012 to January 2013. I will act as a co-supervisor while she is based in Thailand. IPSR has strong relationships with several nongovernmental organisations, including the Service Workers in Group Foundation (SWING), the organisation she intends to involve in her research. We have already informed SWING of Kristel's research intentions and they are interested in her work. Once she has arrived in Thailand, I will assist Kristel to recruit sex workers through SWING, some of whom will have participated in our research assessment. The IPSR research assessment has received Institutional Review Board Approval (IRB) from Mahidol University.

I am fully confident that Kristel's Master's research will make a significant contribution to the academic, health, and practitioner knowledge in her field of Public Health.

Please do not hesitate to contact me if you have any questions or concerns.

Sincerely,



Rebecca Miller, Ph.D
Foreign Expert
Institute for Population and Social Research
Mahidol University
Salaya, Phutthamonthon,
Nakhon Pathom 73170, Thailand
Email: rebecca.mil@mahidol.ac.th
Phone: +66 82 779 8210
Website: www.ipsr.mahidol.ac.th

Appendix 3: Consent form

Consent Form



Project title: *Young sex worker participation in HIV/AIDS policy and programmes in Thailand.*

การเข้ามามีส่วนร่วมของ **Young sex worker** ในเรื่องนโยบาย **HIV/AIDS** และโครงการในประเทศไทย

Project Supervisors: *Dr. Cath Conn, Dr. Shoba Nayar and Dr. Rebecca Miller.*

Researcher: *Kristel Modderman*

☐ I have read and understood the information provided about this research project in the Information Sheet dated **dd mmmm yyyy**.

ข้าพเจ้าได้อ่านและเข้าใจในรายละเอียดของข้อมูลของโครงการวิจัยในเอกสารลงวันที่ dd mmmm yyyy.

☐ I have had an opportunity to ask questions and to have them answered.

ข้าพเจ้าได้มีโอกาสถามคำถามและได้รับคำตอบแล้ว

☐ I understand that notes will be taken during the interviews and that they will also be audio-taped and transcribed.

ข้าพเจ้าว่าจะมีการจดบันทึกระหว่างการสัมภาษณ์และจะมีการอัดเสียงเพื่อการถอดเทปการสัมภาษณ์

☐ I understand that I may withdraw myself or any information that I have provided for this project at any time prior to completion of data collection, without being disadvantaged in any way.

ข้าพเจ้ามีความเข้าใจว่าข้าพเจ้าสามารถถอนตัวจากการเข้าร่วมโครงการหรือข้อมูลที่ได้ให้ไปแล้วเมื่อใดก็ได้ก่อนที่การเก็บข้อมูลจะเสร็จสิ้น โดยจะไม่มีผลเสียประโยชน์ไม่ว่ากรณีใดๆ

☐ If I withdraw, I understand that all relevant information including tapes and transcripts, or parts thereof, will be destroyed.

หากข้าพเจ้าถอนตัว

ข้าพเจ้าเข้าใจว่าข้อมูลที่เกี่ยวข้องซึ่งรวมถึงเทปบันทึกเสียงและบันทึกการถอดเทปหรือส่วนอื่นๆจะถูกทำลาย

☐ I agree to take part in this research.

ข้าพเจ้ายินดีเข้าร่วมโครงการ

☐ I wish to receive a copy of the report from the research (please tick one): Yes ☐ No ☐

ข้าพเจ้าประสงค์จะได้รับสำเนาของรายงานจากโครงการวิจัย ใช่ ☐ ไม่ใช่ ☐

Participant's signature (ลายมือชื่อผู้เข้าร่วม):.....

Participant's name (ชื่อผู้เข้าร่วม):

Participant's Contact Details (if appropriate):

ข้อมูลในการติดต่อผู้เข้าร่วม (หากมีความเหมาะสม)

.....
.....
.....
.....

Date (วันที่):

Approved by the Auckland University of Technology Ethics Committee on 22/11/2012 AUTEK Reference number 12/269

อนุมัติโดย *the Auckland University of Technology Ethics Committee* เมื่อวันที่ 22/11/2012 AUTEK หมายเลขอ้างอิง12/269

Note: The Participant should retain a copy of this form.

หมายเหตุ: ผู้เข้าร่วมควรได้รับสำเนาของเอกสารนี้ด้วย

Appendix 4: Participant information sheet

Participant Information Sheet



ข้อมูลในการเข้าร่วมโครงการ

Date Information Sheet Produced:

วันที่เขียนเอกสารนี้

08 August 2012

8 สิงหาคม 2555

Project Title

ชื่อโครงการ

Young sex worker participation in HIV/AIDS policy and programmes in Thailand.

การมีส่วนร่วมในนโยบายและโครงการที่เกี่ยวข้องกับ HIV ในประเทศไทยของ young sex workers

An Invitation

คำเชิญ

Hello, my name is Kristel Modderman. I would like to invite you to participate in this research project.

I am conducting research that explores how sex workers in Thailand are involved in policy-making and programme development related to HIV. The research will also look at some of the barriers and challenges that prevent young sex workers from being involved in the development of policies and programmes. I am currently enrolled in the Master of Public Health degree at AUT University in New Zealand. This research will contribute to this degree.

Your participation in this research is completely voluntary and you may withdraw at any time.

สวัสดีค่ะ ดิฉันชื่อ Kristel Modderman ดิฉันอยากจะเชิญท่านเข้าร่วมโครงการวิจัยนี้ ดิฉันกำลังทำวิจัยเพื่อดูว่าพนักงานบริการหญิงในประเทศไทยมีส่วนเกี่ยวข้องอย่างไรในการกำหนดนโยบายและการพัฒนาโครงการที่เกี่ยวข้องกับ HIV และงานวิจัยนี้จะศึกษาเรื่องอุปสรรคและข้อท้าทายที่ขัดขวางไม่ให้ young sex workers เข้ามามีส่วนเกี่ยวข้องในการพัฒนานโยบายและโครงการต่างๆด้วย ตอนนี้ดิฉันกำลังศึกษาปริญญาโทด้านสาธารณสุขอยู่ที่มหาวิทยาลัย AUT ในประเทศนิวซีแลนด์ ซึ่งงานวิจัยนี้เป็นส่วนหนึ่งของการศึกษาของดิฉัน

การเข้าร่วมโครงการของท่านจะเป็นไปด้วยความสมัครใจและท่านสามารถถอนตัวออกจากโครงการเมื่อใดก็ได้

What is the purpose of this research?

วัตถุประสงค์ของงานวิจัยนี้คืออะไร?

The primary purpose of this research is to contribute to a Master of Public Health degree. It is hoped that this research will contribute to the small knowledge-base that exists young sex worker input into policy and programme development in Thailand. Policy makers may also refer to this research to help guide their policy development processes.

This research may be used in the development of a paper and/or presented at a conference in the future.

วัตถุประสงค์หลักของงานวิจัยนี้คือเพื่อเป็นส่วนประกอบในการเรียนปริญญาโทด้านสาธารณสุข งานวิจัยนี้หวังจะสนับสนุนฐานความรู้ที่มีอยู่แล้วในประเทศไทยเรื่องการมีส่วนร่วมของ **young sex workers** ในการพัฒนานโยบายและโครงการต่างๆ
ผู้กำหนดนโยบายอาจอ้างถึงงานวิจัยนี้เป็นแนวทางในขั้นตอนการพัฒนานโยบาย

งานวิจัยนี้อาจนำไปใช้ในการพัฒนาเป็นบทความและ/หรืออาจมีการนำเสนอในการประชุมในอนาคต

How was I identified and why am I being invited to participate in this research?

ทำไมท่านจึงได้รับเชิญให้เข้าร่วมโครงการและเราได้รับข้อมูลของท่านได้อย่างไร

You have been identified to be invited to participate in this research as this researcher focuses on services users of SWING aged between 18 and 24 years of age.

เราได้รับข้อมูลของท่านจาก

NGO

เพื่อให้ได้รับเชิญมาเข้าร่วมการวิจัยเนื่องจากงานวิจัยนี้มุ่งเน้นไปยังผู้เข้ารับบริการจาก
ที่มีอายุตั้งแต่ 18-24 ปี

SWING

What will happen in this research?

งานวิจัยนี้จะเกิดขึ้นเมื่อไหร่

If you chose to participate, we would like to ask you some questions around your experience and knowledge of sex worker involvement in policy and programme development. You will also be asked around the barriers that policy makers, programme developers and sex workers might face in this process.

There will be an interpreter present at all times to translate information and help to answer any questions.

All information collected, including your personal information will be kept private and confidential. The data collected will only be used for the purpose it was intended for.

หากท่านตัดสินใจเข้าร่วม

เราจะถามคำถามท่านเกี่ยวกับประสบการณ์และความรู้ของท่านในเรื่องการมีส่วนร่วมของ **sex worker** ในการพัฒนานโยบายและโครงการที่เกี่ยวข้องกับ **HIV** รวมถึงเรื่องอุปสรรคที่ผู้กำหนดนโยบาย, ผู้พัฒนาโครงการ, และ **sex workers** ต้องเผชิญ

จะมีล่ามอยู่ด้วยตลอดการสัมภาษณ์เพื่อแปลข้อมูลและช่วยตอบคำถามต่างๆ

ข้อมูลที่ได้มาทั้งหมด

รวมถึงข้อมูลส่วนตัวของท่านจะถูกเก็บเป็นความลับ

และข้อมูลจะถูกนำไปใช้ในวัตถุประสงค์ที่ตั้งไว้เท่านั้น

What are the discomforts and risks?

ความไม่สบายใจและความเสี่ยงมีอะไรบ้าง

There are no direct discomforts or risks involved. You will not be asked anything of a personal nature. If you feel that the research has caused you any discomfort however, you will have access to free counselling sessions organised through Mahidol University. If you chose to participate, we ask that you do not disclose anything of an illegal nature in the interview. If this occurs, I will need to inform my supervisor.

ไม่มีความไม่สบายใจหรือความเสี่ยงโดยตรง ท่านจะไม่ถูกถามเรื่องส่วนตัว อย่างไรก็ตาม

หากท่านรู้สึกว่าการวิจัยทำให้คุณรู้สึกไม่สบายใจหรือลำบากใจ

ท่านสามารถเข้ารับบริการให้คำปรึกษาซึ่งจัดโดยมหาวิทยาลัยมหิดลได้โดยไม่เสียค่าใช้จ่ายใดๆทั้งสิ้น

หากท่านยินดีเข้าร่วมโครงการวิจัย

เราขอความกรุณาไม่让您เปิดเผยข้อมูลที่ไม่ชอบด้วยกฎหมายในการสัมภาษณ์

หากเหตุการณ์ดังกล่าวเกิดขึ้น นักวิจัยจำเป็นต้องรายงานให้อาจารย์ที่ปรึกษาทราบ

How will these discomforts and risks be alleviated?

ความไม่สบายใจหรือลำบากใจเหล่านี้จะได้รับการบำบัดให้บรรเทาลงอย่างไร

If you feel discomfort during the interviews, please let me know as soon as possible. If you feel that participating in the research would put you at risk, it is advisable that you do not participate.

หากท่านรู้สึกไม่สบายใจหรือลำบากใจ

กรุณาแจ้งให้นักวิจัยทราบทันที

หากท่านรู้สึกว่าการเข้าร่วมโครงการวิจัยนี้จะทำให้ท่านตกอยู่ในภาวะเสี่ยง

นักวิจัยแนะนำให้ท่านไม่ควรเข้าร่วมโครงการวิจัยนี้

What are the benefits?

ผลประโยชน์ที่คาดว่าจะได้รับ

Your involvement in this research will contribute to the current knowledge-base around sex worker input into policy and programme development. This may in turn improve the lives of sex workers in Thailand.

ความร่วมมือของท่านครั้งนี้จะเป็นประโยชน์ต่อฐานความรู้ที่มีอยู่แล้วในปัจจุบันเกี่ยวกับการมีส่วนร่วมของ

sex workers ในการพัฒนานโยบายและโครงการที่เกี่ยวข้องกับ

HIV

ซึ่งในอนาคตจะเป็นประโยชน์ในการพัฒนาคุณภาพชีวิตความเป็นอยู่ของ sex workers

How will my privacy be protected?

ความเป็นส่วนตัวของท่านจะได้รับการคุ้มครองอย่างไร

Yes. Although I will know who you are, all your personal details will be kept confidential and locked in a filing cabinet in my supervisors' office. You may also ask for your personal information back at any time.

ความเป็นส่วนตัวของท่านจะได้รับการคุ้มครอง

ถึงแม้ว่านักวิจัยจะทราบว่าท่านเป็นใครแต่รายละเอียดส่วนตัวของท่านจะถูกเก็บเป็นความลับโดยจะถูกเก็บไว้ในตู้เอกสารและล็อกกุญแจในห้องทำงานของอาจารย์ที่ปรึกษาของนักวิจัย

ท่านสามารถขอข้อมูลส่วนตัวคืนเมื่อใดก็ได้ที่ท่านต้องการ

What are the costs of participating in this research?

การเข้าร่วมโครงการวิจัยนี้มีค่าใช้จ่ายเท่าไร

There are no financial costs to you. If you require travel costs reimbursed, please let me know at the information meeting. In total, a maximum of 300 baht can be given.

The interview will take at a maximum of one hour to complete. I would like to meet you prior to the interview to brief you on the research and answer any questions that you might have.

You will be provided with refreshments at both the meeting and the interview.

การเข้าร่วมโครงการวิจัยนี้ไม่มีค่าใช้จ่ายที่เป็นตัวเงิน หากท่านต้องการเบิกค่าเดินทาง

กรุณาแจ้งให้นักวิจัยทราบในการประชุมเพื่อแจกแจงรายละเอียด โดยจะมีค่าเดินทางที่สามารถเบิกได้สูงสุด 300 บาท

การสัมภาษณ์จะใช้เวลาไม่เกิน 1 ชั่วโมง

นักวิจัยอยากขอให้ท่านมาก่อนเวลานัดเล็กน้อยเพื่อจะได้อธิบายรายละเอียดของงานวิจัย และตอบคำถามของท่านหากท่านมีข้อสงสัย

ในระหว่างการประชุมและการสัมภาษณ์ เราจะมีของว่างไว้รับรองท่าน

What opportunity do I have to consider this invitation?

โอกาสที่ท่านจะได้รับจากการเข้าร่วม

You will be invited to a meeting in December held by me at SWING to learn more about the research. You will also be told about the research in the months leading up to the research. Any questions you have may be directed to the SWING staff or you may contact me or my supervisors directly.

ท่านจะได้รับเชิญให้เข้าร่วมการประชุมในเดือนธันวาคมซึ่งจัดที่

SWING

โดยนักวิจัยเพื่อเรียนรู้เกี่ยวกับรายละเอียดของงานวิจัย

และท่านจะได้รับข้อมูลเกี่ยวกับงานวิจัยล่วงหน้าก่อนที่จะมีการทำวิจัย

หากท่านมีคำถาม

ท่านสามารถสอบถามเจ้าหน้าที่ที่ SWING นักวิจัย หรืออาจารย์ที่ปรึกษาของนักวิจัยได้โดยตรง

How do I agree to participate in this research?

ท่านต้องทำอย่างไรหากยินดีจะเข้าร่วมโครงการวิจัย

If you agree to participate, you will need to fill out a consent form or give verbal consent which will be recorded. This will be done at the interview if you choose to participate.

หากท่านยินดีจะเข้าร่วมโครงการวิจัย

ท่านจะต้องกรอกแบบฟอร์มแสดงความยินยอมหรือแสดงความยินยอมโดยปากเปล่าซึ่งจะได้รับการบันทึกเสียงไว้ในระหว่างการสัมภาษณ์หากท่านตัดสินใจเข้าร่วมโครงการ

Will I receive feedback on the results of this research?

ท่านจะได้รับข้อมูลเกี่ยวกับผลของการวิจัยหรือไม่

Yes. You will receive a copy of the findings. I may return back to Thailand to present the results at SWING.

ท่านจะได้รับสำเนาของรายงานผลการวิจัย นักวิจัยจะกลับมาที่ประเทศไทยและนำเสนอผลการวิจัยที่ SWING

What do I do if I have concerns about this research?

ท่านจะต้องทำอย่างไรหากท่านมีข้อกังวลใจเกี่ยวกับงานวิจัยนี้

Any concerns regarding the nature of this project should be notified in the first instance to the Project Supervisor, Dr. Cath Conn, cath.conn@aut.ac.nz, 0064 9 921 9999 ext 7407.

Concerns regarding the conduct of the research should be notified to the Executive Secretary, AUTEC, Dr Rosemary Godbold, rosemary.godbold@aut.ac.nz, 0064 9 921 9999 ext 6902.

ข้อกังวลใจใดๆที่เกี่ยวข้องกับลักษณะของโครงการวิจัยนี้ควรได้รับการแจ้งไปยังที่ปรึกษาของโครงการวิจัยโดยทันที Dr. Cath Conn, cath.conn@aut.ac.nz, 0064 9 921 9999 ต่อ 7407.

ข้อกังวลใจใดๆที่เกี่ยวข้องกับการดำเนินการวิจัยควรได้รับการแจ้งไปยัง Executive Secretary, AUTEC, Dr Rosemary Godbold, rosemary.godbold@aut.ac.nz, 0064 9 921 9999 ต่อ 6902.

Whom do I contact for further information about this research?

ท่านสามารถติดต่อใครได้หากมีข้อสงสัยเพิ่มเติม

Researcher Contact Details:

ข้อมูลติดต่อนักวิจัย

Kristel Modderman, kristel.modderman@hotmail.com

Project Supervisor Contact Details:

ข้อมูลติดต่อที่ปรึกษาของโครงการวิจัย

Dr. Cath Conn, cath.conn@aut.ac.nz, +64 9 921 9999 ext 7407.

Dr. Shoba Nayar, shoba.nayar@aut.ac.nz, +64 9 921 9999 ext 7304.

Dr. Rebecca Miller, prrebecca@mahidol.ac.th , +66 2441 0201- 4 ext 617

Approved by the Auckland University of Technology Ethics Committee on 22/11/2012

AUTEC Reference number 12/269.

Appendix 5: Interview questions

How important is it for young sex workers to participate in the development of HIV policies and programmes?

การเข้ามามีส่วนร่วมของ young sex worker ในการพัฒนานโยบายและโครงการเกี่ยวกับ HIV มีความสำคัญอย่างไร

Have you been involved in the development of any HIV policies or programmes?

ท่านเคยมีส่วนร่วมในการพัฒนานโยบายหรือโครงการที่เกี่ยวกับ HIV หรือไม่

If yes, can you describe your involvement?

หากเคย ท่านมีส่วนร่วมอย่างไร

Without giving specific details, such as names or places of work, do you know of other sex workers who have been involved in the development of HIV policies or programmes?

ท่านรู้จัก sex workers คนอื่นๆที่เคยมีส่วนร่วมในการพัฒนานโยบายหรือโครงการที่เกี่ยวกับ HIV หรือไม่ กรุณาตอบคำถามโดยไม่ระบุรายละเอียดเกี่ยวกับบุคคลนั้นๆ เช่นชื่อหรือสถานที่ทำงาน เป็นต้น

In your experience, where are the gaps in current HIV policies and programmes targeted at young sex workers?

จากประสบการณ์ของท่าน นโยบายและโครงการที่เกี่ยวกับ HIV

ในขณะนี้มีส่วนไหนหรืออย่างไรในการการเน้นความสำคัญไปยัง young sex workers

What barriers exist to young sex workers participating in HIV policy and programme development?

อุปสรรคของ young sex workers ในการเข้ามามีส่วนร่วมในการพัฒนานโยบายหรือโครงการที่เกี่ยวกับ HIV คืออะไร

Do you think that greater participation of young sex workers in HIV policies and programme development will improve the lives of young sex workers?

ท่านคิดว่าการเข้ามามีส่วนร่วมในการพัฒนานโยบายหรือโครงการที่เกี่ยวกับ HIV ของ young sex workers จะทำให้ชีวิตความเป็นอยู่ของพวกเขาดีขึ้นหรือไม่