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Combating HIV/AIDS in Marginalized Communities: Papua and West Papua Provinces, Indonesia

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Abstract

My study focuses on foreign aid and local initiatives for HIV/AIDS prevention in eastern Indonesia using the provinces of Papua and West Papua as a case study. The two provinces are home to indigenous tribal groups that are socioeconomically marginalized and most affected by the epidemic. My research investigates behavior change communication as a principal strategy undertaken by multiple organizations for HIV/AIDS prevention in this region. I take a qualitative approach by examining the effectiveness of this strategy in local communities and by revealing social and cultural barriers that impede success. Obstacles that negatively impact prevention efforts include structural violence, stigma and discrimination. I identify areas, such as targeted health messaging, where HIV/AIDS prevention efforts can be improved to benefit marginalized communities.

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Acronyms and Abbreviations

ABC	Abstinence, Be Faithful, Condom use
AIDS	Acquired Immunodeficiency Syndrome
AIPH	Australia Indonesia Partnership for HIV
ART	Antiretroviral Therapy
AUD	Australian Dollar
AusAID	Australian Agency for International Development
BCC	Behavior Change Communication
CSO	Community Service Organization
DOD	Department of Defense
FBO	Faith Based Organization
FHI 360	Formerly Family Health International
FSW	Female Sex Workers
GFATM	The Global Fund to Fight AIDS, Tuberculosis and Malaria
GOI	Government of Indonesia
HAPP I&II	HIV/AIDS Prevention Project
HIV	Human Immunodeficiency Virus
IDUs	Injecting Drug Users
IEC	Information, Education and Communication
IRIN	Integrated Regional Information Networks
MDM	Médecins du Monde

MOH	Ministry of Health
MSM	Men who have sex with men
NGO	Non-governmental Organization
ODC	Offices of Defense Cooperation
PEPFAR	President's Emergency Plan for AIDS Relief
POC	Point of Contact
SCC	Social Change Communication
STD	Sexually Transmitted Disease
SUM I&II	Scaling up Most at Risk Populations
UNAIDS	United Nations Programme on HIV/AIDS
UNICEF	United Nations Children's Fund
U.S.	United States
USAID	United States Agency for International Development
VCT	Voluntary Counseling and Testing
Waria	Transgender persons
WHO	World Health Organization
YKB	Yayasan Kesehatan Bethesda or Bethesda Health Foundation

Chapter One: Introduction

1.0 Introduction

Since the emergence of the Human Immunodeficiency Virus (HIV) and Acquired Immune Deficiency Syndrome (AIDS) over 30 years ago, 60 million people have been infected worldwide, resulting in approximately 25 million deaths (Laksono 2010,14). HIV is a persistent, deadly and infectious virus that if not treated causes AIDS (Turk, Ewing and Newton 2006, 333). It is spread by the exchange of bodily fluids such as through unprotected sex with an infected person and by sharing contaminated needles. The virus can also spread through childbirth and breastfeeding. The sexual transmission of HIV/AIDS can be prevented with the use of condoms. There is no known cure for the disease, but long-term antiretroviral therapy (ART) is available and can prolong life. Antiretroviral treatment is also a form of prevention and an important component to managing HIV/AIDS (World Health Organization-HIV/AIDS n.d.).

There are five countries that account for 99% of the HIV burden in Southeast Asia. These countries include Indonesia, India, Nepal, Myanmar and Thailand. In this region approximately 220,000 people die each year from the disease (Plianbangchang 2011) (Aids2014 2014).

1.1 Statement of the Problem

This study examines the prevalence (percent or proportion of people with HIV at a given time) of HIV/AIDS in Indonesia, particularly in its eastern provinces of Papua and West Papua also known as *Tanah Papua*[1]. Prior to being known as *Tanah Papua*,

[1] "*Tanah* is the Malay and Indonesian word for 'land', so *Tanah Papua* means 'Land of Papua'" (Gil 2014).

from 1973 to 2002 the province of Papua was officially known as *Irian Jaya* or the western half of New Guinea (Munro 2004). In 2007, the province of Papua was divided into Papua and West Papua (Butt 2008, 118). In *Tanah Papua* the prevalence of HIV/AIDS is 15 times higher than the national average (Butt, Numbery and Morin 2002, 283; USAID Indonesia 2014). The epidemic is in a *generalized*[2] stage, exceeding the national average of 0.3% (Plianbangchang 2011; Reckinger and Lemaire 2013). In these two provinces, the virus is mostly transmitted through heterosexual sex and the overall affected population is between 15 and 49 years of age (Laksono 2010, 11). As I discuss in chapter two, the HIV/AIDS rates are twice as high in the indigenous population than the non-indigenous in-migrants.

This region is a useful case study in the context of HIV/AIDS because of the high prevalence of the disease among the geographically isolated and socioeconomically marginalized indigenous populations such as the Dani ethnic group[3]. The marginalization of the indigenous Papuans is a result of complex ethno-religious differences with the Malay-Indonesians, also known as "in-migrants," who moved to *Tanah Papua* after 1969 when the provinces became a part of Indonesia (Butt, Numbery and Morin 2002, 282). Approximately 73% of all indigenous Papuans live along the coast or in the highlands; these are rural, underdeveloped regions with no roads, few schools, and inadequate health infrastructure (International Labour Organization (ILO) 2012-2013). In addition to their geographic isolation and marginalization, there are high levels of economic and social inequality between the indigenous groups and in-migrants based on their past colonial

[2] According to WHO when HIV is over 1% in the general population and HIV infection is monitored in the general population, it is a generalized epidemic.
[3] The Dani ethnic group is one of most widely known indigenous groups in Papua central highlands in the Jayawijaya Mountains.

structures and relationships. The indigenous Papuans are racially and culturally different than the Indonesian in-migrants, distinguished by their skin tone, hair, diet and traditions.

As I discuss in chapter four, the indigenous groups are extremely disadvantaged in comparison to the in-migrants. Two-thirds of the indigenous population cannot read or write. This population also has poorer health than the in-migrants. For example, Susan Rees *et al*. find that the maternal mortality rate is three times higher in *Tanah Papua* than in other Indonesian provinces due to the lack of access to health facilities. Further, there is a lack of awareness about HIV/AIDS among the indigenous groups that is exacerbated by the lack of adequate health services as well as the mistrust of the Indonesian government and in-migrant health practitioners. Some indigenous people believe that the health facilities are part of the "Indonesian Colonial Machinery" and that HIV was introduced into indigenous communities to annihilate them (Reckinger and Lemaire 2014). Moreover, extreme poverty in the rural areas of *Tanah Papua* is said to be approximately 36%, which is double that of the national average. The indigenous population also faces an oppressive social, cultural and political environment as a legacy of the Dutch colonial past (International Labour Organization (ILO) 2012-2013; J. Elmslie 2013).

Despite the efforts of multiple organizations working in HIV/AIDS in *Tanah Papua*, little development has taken place to improve education and health infrastructure in rural areas, and the HIV/AIDS rates are rising among the indigenous groups. Since the prevalence of disease is higher in the indigenous population compared to the non-indigenous Indonesian in-migrants, it is important to find why this difference exists. In this study, I address the following questions:

- Why are HIV/AIDS rates climbing in *Tanah Papua* among the indigenous Papuans, despite multi-agency prevention programs?
- What are the current approaches toward HIV/AIDS prevention?
- How are these approaches effective or ineffective?
- Who are the most-at-risk social groups and how have programs attempted to reach them?
- What are the main barriers to effective HIV/AIDS prevention?
- How are local communities considered in the design and implemnetation of HIV/AIDS prevention programs?
- What implementation models are having the greatest impact to manage HIV/AIDS?

1.2 Purpose and Significance

Finding effective HIV/AIDS prevention strategies has proven challenging for this area because of the influence of structural violence[4] and a turbulent socio-economic, cultural and political environment that has continued since *Tanah Papua* became part of Indonesia. As I discuss later in chapter four, in addition to the geographic isolation, structural violence has created challenging social barriers for HIV/AIDS programs in this region. It has also exacerbated the marginalization, stigma and discrimination against the indigenous people.

There are multiple organizations and countries working in *Tanah Papua* to address the problem of HIV/AIDS. Due to the above-described barriers, it is difficult for HIV/AIDS prevention programs implemented by local and international organizations to

[4] The systematic exclusion of people from basic human needs such as health care and education that is detrimental to life.

achieve desired results. HIV/AIDS programs implemented in *Tanah Papua* are based on the theory of "behavior change communication" that implies the use of communication strategies to promote positive behaviors in communities. For example, one strategy is to promote methods of prevention, such as condom use, among Papuans. Because such campaigns ignore the socio-cultural context of the indigenous Papuans, it is difficult for the marginalized communities to understand HIV/AIDS, prevention and its modes of transmission.

Other researchers have examined the HIV/AIDS epidemic in *Tanah Papua*, but from a limited and specific standpoint, in that most literature is focused on analyzing isolated topics in relation to the public health problem. For instance, different studies discuss foreign assistance effectiveness, or stigma and discrimination, or social marginalization, independently. My work adds to the existing literature by providing a deeper analysis of the social and cultural aspect of the problem and draws on other scholarly research to synthesize all the important components for HIV/AIDS prevention. I apply the experiences of the indigenous Dani ethnic group to show the inequalities faced by this population. I also describe commercial female sex workers to explain why and how HIV/AIDS campaigns are ineffective among these marginalized groups in *Tanah Papua*. I argue that future prevention strategies need to integrate indigenous culture and traditions, develop strategies to address barriers (such as stigma and discrimination), and improve health service delivery for indigenous Papuans.

1.3 Theoretical Framework

My research draws on four bodies of literature to assess why HIV/AIDS prevalence is on the rise in *Tanah Papua.* These include: (i) foreign assistance, economic

growth and health; (ii) social and cultural anthropology; (iii) behavior change theory in communication; and (iv) the growing role of civil society, non-governmental, and faith based organizations in HIV/AIDS prevention.

1.4 Chapters Summary

1.4.1 Chapter Two: Background

In chapter two, I provide a context in which to analyze HIV/AIDS prevalence in *Tanah Papua.* I include background information on Indonesia and *Tanah Papua* relevant to the problem of HIV/AIDS. I also discuss the prominent bilateral, multilateral donors and organizations working on HIV/AIDS control, prevention, and treatment. I end this chapter with a brief description of the delivery of health services in *Tanah Papua*.

1.4.2 Chapter Three: Methodology

In this chapter, I present my methodology for the study. I used the qualitative method to find and analyze data. My study relies on library/desktop research and phone interviews. My sources improve understanding on this subject and help identify gaps in the academic literature and current approaches to HIV/AIDS prevention. I also searched key websites including USAID (United States Agency for International Development), WHO (World Health Organization), and AusAID (Australia Agency for International Development) and found evaluation reports and audits of programs by scholars, economists, policy consultants and field workers. I searched for key terms such as "HIV/AIDS," "*Tanah Papua*" and "prevention," using multiple search engines, databases and websites. My key word research returned articles from peer reviewed journals.

1.4.3 Chapter Four: Literature Review

In the literature review, I examine arguments made by other researchers in

relation to the rising HIV/AIDS rates among indigenous Papuans. I present the debate on foreign assistance and review arguments on foreign assistance for HIV/AIDS. I consider the prevention strategies being implemented in *Tanah Papua* and examine the behavior change communication approach undertaken for HIV/AIDS prevention. Finally, I present the interlinked barriers, including structural violence, to HIV/AIDS prevention.

1.4.4 Chapter Five: New Data, Thesis Conclusion and Recommendations

In this chapter, I provide new data on additional barriers to HIV/AIDS prevention programs in Indonesia at district and provincial levels. I provide data on the current approaches being implemented and also highlight major themes such as stigma and discrimination. I present a conclusion based on my research and findings. Finally, I make recommendations on what can be done in *Tanah Papua* to improve HIV/AIDS prevention strategies for marginalized communities and to fight the epidemic.

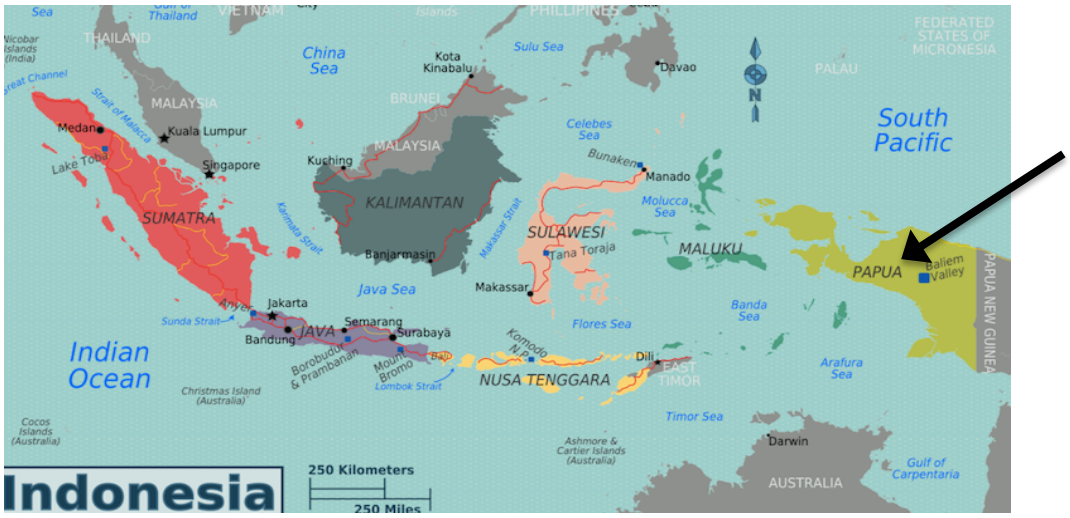
Chapter Two: Background

2.0 Introduction

In this chapter, I first review the historical background on Indonesia and present data on HIV/AIDS rates in the country. Second, I provide background on *Tanah Papua* and describe the epidemic in its two provinces. In section three, I describe the prominent bilateral and multilateral donors working with the Government of Indonesia by providing support at district and provincial levels. This section is divided by separate subheadings for each donor agency. Finally, I discuss the delivery of health services in *Tanah Papua*.

2.1 Indonesia

Figure 1: Map of Indonesia



Source: http://mapsof.net/map/indonesia-regions-map

Indonesia is an archipelago of 17,000 islands that hosts a population of approximately 250 million people (World population review 2013). It has the fourth largest population in the world and is a predominantly Muslim country. Indonesia has 33 provinces that are further divided into 500 districts (Laksono 2010, 11). The political

capital of Indonesia is Jakarta. In 2001, the country underwent a decentralization[5] process that devolved responsibilities from the center to provincial and district levels. For example, the authority to deliver health services transferred from the Ministry of Health (MoH) at the central level to district offices (Heywood and Choi 2010, 2).

Prior to Indonesia's colonization by the Dutch in 1600, it had a trading economy based on domestic commodities, such as spices, pepper and gold (Kahn 1982). Although the trading economy of the country is beyond the scope of this paper, it is relevant in order to understand the situation in *Tanah Papua.* The highlands are rich in timber, gold and copper. In the 1960s the Grasberg mine was established and owned by Freeport-McMoran, the largest international mining company that produces gold and copper (Schiffman and Corbin 2007). Currently, Indonesia has a gross domestic product (GDP) of USD$1 trillion and is a major economic partner with the United States (USAID, Indonesia 2014). Despite its growing economy, approximately 40 million people or about one out of sixth of people in Indonesia currently live below the international poverty line of $1.25 a day (USAID, CDCS Indonesia 2014).

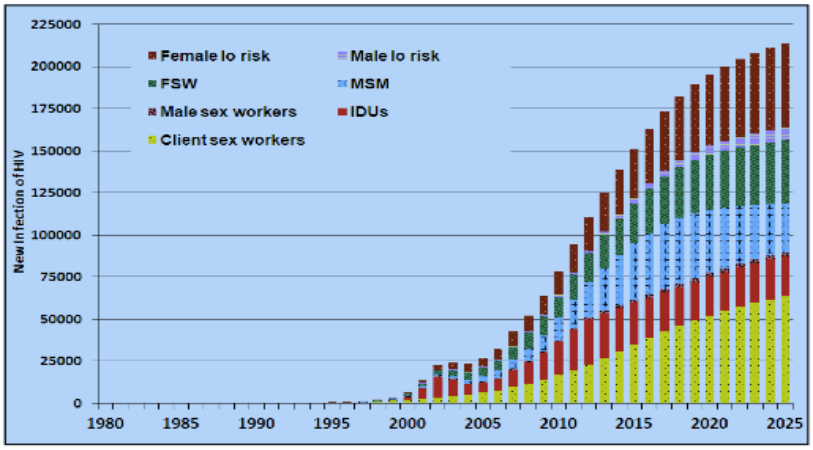
2.1.1 HIV/AIDS in Indonesia

The first case of AIDS in Indonesia was reported in Bali in 1987 (Laksono 2010, 14). By 2000, the number of HIV/AIDS cases in Indonesia had risen gradually to 225 people. By 2006, 7,195 people were infected and five years later the numbers rose to 76,879 people (Laksono 2012, 1; MoH, Year end Report on Situation of HIV and AIDS in Indonesia, 2006 and 2011). Currently about 480,000 people in Indonesia are living with HIV/AIDS, or approximately 0.19% of the Indonesian population (United States

[5] Central government has overall regulatory function but responsibilities for planning, financing and distribution of services lie with local governments (World Bank 2008). Decentralization is relevant to the background only and is otherwise beyond the scope of this paper.

Agency for International Development Indonesia 2014). The Indonesian Ministry of Health predicts that the number of people infected with HIV/AIDS will increase to 541,700 by the end of 2014. Indonesia's increase in HIV/AIDS prevalence is one of the most rapid in Asia (Hind *et al*. 2011, xi).

Figure 2: The Potential Future Trend for HIV in Indonesia



This modeling is based on demographic, behavioral, and epidemiological data of the respective populations to illustrate the distribution of infection.

Source: (Laksono 2010, 15)

HIV is most prevalent among injecting drug users, transgender people (*waria*), men who have sex with men (*MSM*) and commercial sex workers. It is also transmitted during birth and breastfeeding. These risk groups constitute a *concentrated*[6] epidemic (rapid spread of the disease) in Indonesia (Laksono 2010, 14). The epidemic is largely driven by unprotected sexual intercourse with an infected person, and by sharing of infected needles among injecting drug users (IDUs). Mother to child transmission of HIV is low. Data from 2008 to 2014 shows that HIV transmission by sexual relations has increased from 43% to 58% while transmission by IDUs decreased from 53% to 34% (Laksono 2012, 15). Indonesia has an active commercial sex industry and the use of

[6] According to the WHO: A *concentrated* epidemic means when HIV is over 5% in any sub-population at higher risk of infection such as sex workers and particularly those groups are monitored.

condoms is noted to be "low," placing sex workers and their clients in a high risk category for contracting HIV/AIDS (Laksono 2011, 56). In 2008, the overall sex worker population was estimated to be anywhere from 200,000 to 300,000 with a clientele of over four million people (Kendall and Razali 2010).

Although the sex industry employees are male, female, *waria* and *MSM*, my study mainly investigates female sex workers and their clients. I discuss this further in chapter four. Evidence shows there are approximately 190,000 to 270,000 female sex workers (FSWs) in Indonesia (Riono and Jazant 2004, 82). Data from Integrated Biological and Behavioral Surveillance Surveys (IBBS) in 2011 confirms that overall 10% of "direct" female sex workers (women who work in brothels and on the streets) and three percent of "indirect" FSWs (women who work in bars and massage parlours) have HIV. One in four HIV positive women in Indonesia are below the age of 25 years (Plianbangchang 2011, 24).

2.2 *Tanah Papua*

Figure: 3 Map of Papua and West Papua Provinces

Source: http://www.boelenspythons.com/naturalhistory

After *Tanah Papua* gained independence from the Netherlands in 1962 the Indonesian military occupied *Tanah Papua*. This region has a politically volatile environment because of ethno-religious and racial disparities among population groups (Rees *et al*. 2008). One of the reasons for these disparities is the "transmigration initiative". The Dutch colonial government introduced the transmigration initiative in 1905, to reduce the burden of overpopulation on the island of Java by encouraging people to move to less populated provinces, such as *Tanah Papua* (Fearnside 1997, 553). The Indonesian government also encouraged in-migrants to move to *Tanah Papua* by promising better economic opportunities and employment in the natural resources industry (Hedman 2008, 150). Consequently, the population demographics in this province began to change, as I discuss further in chapter four.

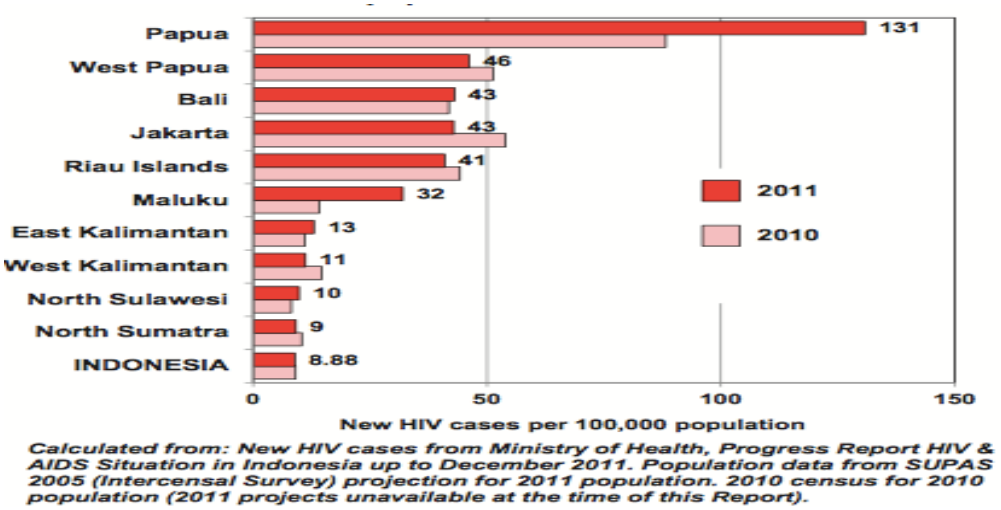
Currently, *Tanah Papua* has a population of approximately 1.2 million indigenous Papuans who are descendants of Melanesia and are predominantly animist or Christian converts. Close to one million Malay-Indonesians, also referred to as in-migrants, are predominantly Muslim (Butt, Numbery and Morin 2002, 283). *Tanah Papua* has approximately 260 Indigenous Papuan tribes (Reckinger and Lemaire 2013). The Dani ethnic group is one of the largest of the indigenous groups. The Dani people live in the Papua central highlands in the Jayawijaya Mountains and largely practice subsistence agriculture (Schwimmer 1997).

2.2.1 HIV/AIDS in *Tanah Papua*

A World Health Organization (WHO) report shows that the HIV/AIDS rates vary widely by region in Indonesia. In *Tanah Papua,* located 2,000 km east of Jakarta, the prevalence rate of HIV/AIDS is "20.4 cases per 100,000" people, compared to the

national rate of "0.42 per 100,000" infected people in the rest of Indonesia. As noted previously, the rates are twice as high in the indigenous population than the non-indigenous and in some areas Papuans constitute 80% of the cases. Figure 4, below shows the HIV/AIDS prevalence in Papua and West Papua.

Figure 4: Prevalence of New HIV Cases per 100,000 population in 2011



Source: (United Nations Children's Fund Indonesia 2012; Pas 2008)

Figure 5: Population and HIV/AIDS Rates in *Tanah Papua*

Population	Prevalence Rate
General Population	2.4%
Adult Male	2.9%
Adult Women	1.9%
Indigenous	2.8%
Non-indigenous	1.5%

Source: (United Nations Children's Fund Indonesia 2012; Pas 2008)

In West Papua, the prevalence of HIV/AIDS in all adults is projected to rise to seven percent by 2025 (Rees *et al*. 2008, 642), forming a *concentrated stage* (Riono and Jazant 2004, 78) of the epidemic. Butt, Numbery and Morin also find that the Papua province comprises about 40% of HIV/AIDS cases in Indonesia and this province represents less than one percent of the total Indonesian population (Butt, Numbery and Morin 2002, 283). The main drivers of the epidemic in *Tanah Papua* are female sex workers (FSWs) and their clients who are geographically mobile and do not use condoms (Plianbangchang 2011, 23). Sex workers in the Papua province are mostly women of Papuan and Malay-Indonesian (in-migrants) descent. HIV/AIDS interventions do not reach both groups equally; as a result Papuan women are at higher risk of HIV infection than Indonesian women. There are about 12,000 sex workers in the province who do this work on a temporary basis to survive. Of the 12,000, approximately 4,000 sex workers are regulated by the government and work within fixed and safe places, such as sex centers and bars, while the remaining 8,000 are known to work independently on the street, or in a more secretive way across rural areas, making them more vulnerable. The 4,000 sex workers who are regulated get precedence in interventions, as the ones who operate independently are harder to reach (Butt, Numbery and Morin 2002 285, 286).

According to researchers Carole Reckinger and Antoine Lemaire, the most recent data indicates that 13,836 people have tested positive for HIV in *Tanah Papua* (Reckinger and Lemaire 2013). They state that the numbers for HIV infections are inconsistent particularly in the Papuan highlands. Due to the physical and geographic isolation of the people, not everyone has been tested and therefore the infection rates are underreported. For example, data collected by non-governmental organizations (NGOs)

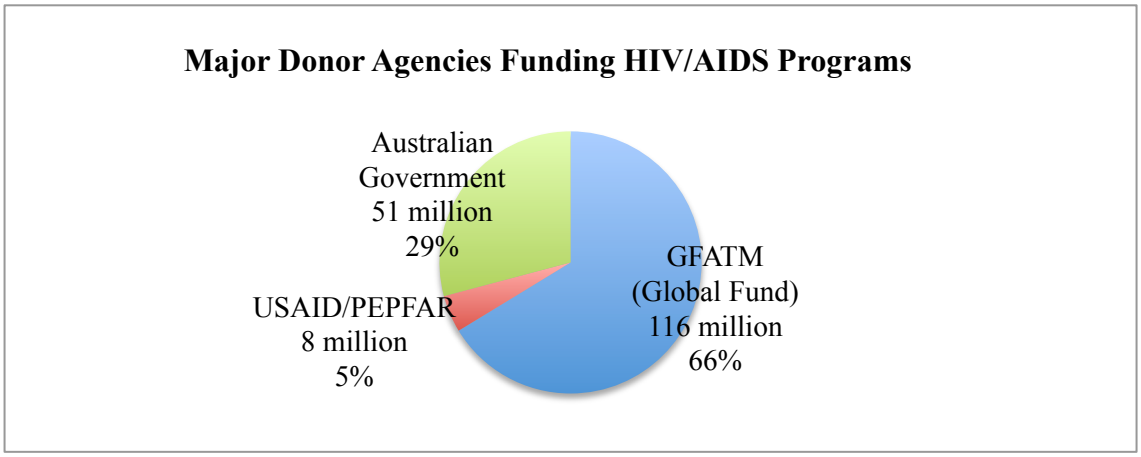
and voluntary counseling and testing (VCT) centers in the Jayawijaya region indicates 3,257 people tested positive for HIV as of July 2013. NGOs suggest that this number is probably not accurate (Reckinger and Lemaire 2013). The growing epidemic in *Tanah Papua* has gained the attention of multiple foreign agencies, which have focused their assistance on halting the epidemic in this region.

2.3 International Assistance to Fight HIV/AIDS

Indonesia relies on foreign assistance or aid funding for HIV/AIDS prevention programs, capacity building of institutions at national and local levels and technical assistance to enhance programs. In 2012, there were over ten donor agencies committed to providing aid to Indonesia (Dugay 2012). However, the Global Fund to Fight AIDS, Tuberculosis and Malaria (GFATM), The U.S. President's Emergency Plan for AIDS Relief (PEPFAR) and the Australian government are the major financers of HIV/AIDS programs in Indonesia (Peiffer and Boussalis 2010, 561). The Global Fund receives funding from multiple countries, while PEPFAR is an initiative of the U.S. government. The Australian and U.S. governments remain the largest bilateral donors in aid directed toward HIV/AIDS. Donor agencies that work under bilateral assistance vary in their programs, approach and funding mechanisms, depending on respective agendas and concerns, such as economic partnerships, democracy building, gender inequality and geo-politics (Renzio and Rogerson 2005). The donor agencies provide funding for programs while the implementation partners manage and facilitate these programs. The multiplicity of agendas and the involvement of many stakeholders, such as national governments, their internal ministries, multilateral organizations and NGOs as implementation partners, result in a complex array of assistance programs.

The multiple assistance organizations aim to support the Government of Indonesia's (GOIs) approach to fighting HIV/AIDS in Indonesia. The Government of Indonesia has a comprehensive national HIV/AIDS strategy implemented by the National AIDS Commission and the Ministry of Health. The approach identifies four key areas to combat HIV/AIDS, including: (i) prevention; (ii) care, support and treatment; (iii) impact mitigation; and (iv) conducive environments (Laksono 2010, 33).

Figure 6: Shows funding given by multilateral and bilateral agencies to Indonesia and *Tanah Papua,* 2014



As seen in Figure 6, GFATM is the major organization funding HIV/AIDS programs with US$116 million allocated to Indonesia for the years 2014 to 2016 (The Global Fund to Fight AIDS, Tuberculosis and Malaria 2014). PEPFAR/Indonesia has helped the Government of Indonesia with building its capacity at national and local government levels to implement, plan, monitor and evaluate programs at a countrywide level (PEPFAR 2013). It has provided approximately US eight million dollars in funding. In 2012, of the US$24 million in total funding for prevention (domestic and international), US two million dollars were spent on prevention in the Papua province (2012 National AIDS Spending Assessment report).

The Australian and U.S. governments are implementing a number of programs with the help of their implementation partners that are focused on providing technical support, capacity building, and HIV/AIDS prevention and treatment in Indonesia.

Figure 7: List of implementation partners

- Non-governmental Organizations
- Civil Society Organizations
- International Non-governmental Organizations
- Private Sector
- Faith Based Organizations

2.3.1 Australia

The Australian government has supported Indonesia for more than 16 years with the most recent Australia Indonesia Partnership for HIV (AIPH) initiated in 2008 to 2016 (Hind *et al*. 2011, xiii). Due to its close proximity to Australia, Indonesia relies heavily on AIPH, which provides funding for HIV/AIDS programs and uses behavior change communication for HIV/AIDS prevention and to slow the spread of the disease (Hind *et al*. 2011, xiii).

2.3.2 Australia & Implementation Partners

Just like the U.S., the Australian government through its Department of Foreign Affairs and Trade provides funding and support to its implementation partners working in HIV/AIDS in *Tanah Papua*. These organizations, and funding amounts are listed below in Australian Dollars (AUD)[7]:

- The Clinton Health Access Initiative (CHAI) is funded by the Australian

[7] One Australian Dollar equals US$0.87

government and managed by the Clinton Foundation. It addresses the biomedical (includes care, support and treatment) aspect of HIV/AIDS and received over four million dollars from 2010 to 2012.

- HIV Cooperation Program for Indonesia (HCPI) also works in prevention of HIV. Gunn Rural Management International manages the program, supplying and supporting the Provincial AIDS Commission. This program received a funding amount of approximately $45 million from 2008 to 2013.
- The Indonesia Partnership Fund for HIV (IPF) provides funds to national, provincial and district AIDS Commissions and received one million dollars per year from 2011 to 2013 (Hind *et al*. 2011, xiii; Australian Government Department of Foreign Affairs and Trade 2013).

2.3.3 United States

The United States and Indonesian bilateral partnership is over 50 years old and is based on mutual interests (USAID, Indonesia 2014) to increase Indoensia's capacity in health services and help it advance economically. However in the context of health, the new U.S. foreign aid strategy for Indonesia (implemented by USAID) is focused more on capacity building of local organizations and providing technical assistance. It is also supported by the more recent U.S. President's Emergency Plan for AIDS Relief (PEPFAR) to improve health care services at local levels (USAID Strategy For Indonesia 2014-2018 2013).

2.3.4 United States & Implementation Partners

In *Tanah Papua,* PEPFAR/Indonesia has two program implementation partners: USAID and the United States Department of Defense (DOD) that operates through the

Office of Defense Cooperation (ODC). PEPFAR reinforces the need for an assertive strategy for condom use and provides technical assistance to USAID with service delivery. This includes addressing the supply and demand of condoms. The ODC trains the Indonesian military and Ministry of Defense and provides technical assistance for prevention, care and treatment (PEPFAR 2013, 3).

Increasing the capacity of civil society organizations (CSOs) is an important element to reaching most at risk populations. PEPFAR also supports the Government of Indonesia by expanding the capacity of local civil society organizations, non-governmental organizations and the provincial governments, in an effort to increase the effectiveness of HIV/AIDS prevention programs (GHI 2011). For example, Scaling up for Most at Risk Populations (SUM) I and (SUM) II are the new technical assistance programs by PEPFAR/Indonesia, implemented by FHI360 (formerly called Family Health International, a non-profit and human development organization). They work with national participants and CSOs to strengthen the links between various HIV prevention sites. The Kinerja[8] program is another local governance service improvement program that is operating in about 20 districts. It is working to improve public services and build stronger health service delivery systems in Papua (PEPFAR 2013).

Futures Group, a global health consulting firm and *DKT International*, a private non-profit, have also implemented HIV/AIDS prevention strategies in Indonesia. These private sector groups are among the U.S. implementation partners that use communication for HIV/AIDS prevention. They impart HIV/AIDS information and education through social marketing tools, and modes of mass and social media (Cullen 2009). From 1996 to 2000, *Futures Group* implemented an HIV/AIDS Prevention Project

[8] Means performance in Indonesia.

(*HAPP) I & II*, funded by USAID and managed by FHI 360 formerly Family Health International (Future's Group n.d.).

The *Futures Group* partnered with condom manufactures to conduct a three month long campaign called "Kondomania" that focused on sales and condom advertisements. Education about condom usage in red light districts was part of this strategy. The *Futures Group* piloted entertainment events and media gatherings to educate people about sexually transmitted diseases (STDs)/HIV/AIDS and condom use. Some of the events included "street dramas, street music, dance competitions, radio talk shows conducted live in bars or discos, kite festivals, car rallies, and karaoke" (Futures Group Indonesia n.d.)[9].

2.3.5 Non-governmental and Faith Based Organizations

A number of NGOs, such as *Médecins du Monde* (*MdM*) and faith based organizations (FBOs) like Bethesda Health Foundation, also known as Yayasan Kesehatan Bethesda (*YKB*), are involved with local communities to provide care and prevention information. In 2009, *Médecins du Monde* (*MdM*) started working with indigenous Papuans from the *Puncak Jaya* district. The initiative is focused on improving medical aid and health of people living in the highlands. It works on developing new prevention strategies while encompassing the socio-economic, political and cultural conditions of highlanders. For example, *Médecins du Monde* used an information, education and communication approach through peer education and condom demonstrations during educational workshops. The workshop organizers drew simple images of people having sexual intercourse to make it easier for the Dani indigenous people to understand how HIV/AIDS is transmitted (Simonin, Bushee and Courcaud

[9] bani.cheema@wordpress.com

2011).

The involvement of FBOs in HIV/AIDS prevention efforts is controversial because some religious groups do not condone discussions of sexual behaviors. In *Tanah Papua*, the Bethesda Health Foundation (*YKB*) is a Christian organization that works with leaders of local churches, rural communities, street children and people living with HIV/AIDS. Because many Papuans are influenced by religious ideologies and a moralist approach, *YKB's* information about HIV/AIDS prevention is better understood (requoted in Simonin, Bushee and Courcaud 2011, 190; Butt, Numbery and Morin 2002). I describe an example of this approach in chapter four.

Despite the efforts of above organizations, HIV/AIDS prevalence rates in *Tanah Papua* are not decreasing. Data from the Indonesian Central Statistics Agency shows that 52% of Papuans have not heard about HIV/AIDS and a high 65% were unaware of using condoms as a means of prevention from the virus (requoted in Simonin, Bushee and Courcaud 2011,186; Indonesian Central Statistics Agency 2007). One major concern is the coordination of the partnership mechanisms. The AIPH review states that the efforts are not well harmonized as a result of inefficiency and pluralistic grant mechanisms (Hind *et al*. 2011, 24, 25). They suggest that Global Fund grant initiatives provide more favorable incentives for staff than the Ministry of Health. This tactic draws staff away from local governments creating an internal "brain drain" that hinders the capacity of the domestic health service delivery system (Hind *et al*. 2011, 29).

2.4 Delivery of Health Services

According to the 1945 Constitution of Indonesia, health is identified as "a means to promote public welfare and the development of human capital as a national priority"

(Spratt *et al*. 2007, 3). An audit published in 2007 by USAID's Health Policy Initiative on Indonesia's HIV/AIDS strategy shows that post decentralization, the legal framework for the Indonesian health system has remained unchanged (Spratt *et al*. 2007, 3). According to the National AIDS Commission, National HIV and AIDS Strategy and Action Plan 2010-2014, although there was an increase in domestic funding for HIV/AIDS in 2004 from (USD 0.18/capita to USD 0.23/capita in 2008), the service delivery and functions of the public health system remain stagnant (Laksono 2010, 22). A more recent audit of the USAID Indonesia's Kinerja Program the local governance service improvement program, issued by the Regional Office of Inspector General USAID in November 2013, suggests an ongoing need for foreign technical support at district levels in Indonesia (Murphy 2013). Scholars Kiat Ruxrungtham, Tim Brown and Praphan Phanuphak argue that Indonesia's efforts to scale up its HIV/AIDS response needs to be met with co-ordination and careful planning at all levels of government in order to reach all population groups (Ruxrungtham, Brown and Phanuphak 2004, 76).

The local health system operates with minimum funds, lack of resources and staff, making the health system fragile and creating gaps in the implementation of prevention programs developed by donor agencies. Most health facilities are located in urban areas and there are few testing locations in the highlands (Butt, Silence Speaks Volumes 2008, 122). According to Integrated Regional Information Networks (IRIN) data collected from 2012, the ratio of doctors and nurses to the population was 2: 10,000 and 17:10,000 respectively, much lower than the minimum requirement of the World Health Organization that is 23:10,000 (Integrated Regional Information Network 2014).

A report by the district office of *Puncak Jaya* District and *Médecins du Monde* indicates that only eight percent of the budget is allotted to health services (Rees *et al*. 2008). The data for health facility budgets in the Province of Papua is limited. A report by the Indonesian Department of Health shows that only one hospital with 70 beds serves a population of 400,000 in the central highlands, an area of about 53,000 square kilometers. There are approximately 15 health centers with one doctor across 13 sub districts (West Papua Information Kit n.d.). Most affected by this physician shortage are the indigenous people who reside in Papuan highlands or rural areas that remain untouched by the development that is taking place in cities. Often, HIV/AIDS campaigns are unable to reach Papuans living in the highlands due to the lack of roads and their geographic isolation. The weak health infrastructure in this region is ill prepared to serve its population. There are also other explanations for the gaps in services, as I discuss in chapter four.

Chapter Three: Methodology

3.0 Introduction

The remote geographic location of *Tanah Papua* makes these provinces difficult for researchers to access. For these reasons, I was unable to go into the field to conduct my research. I used mostly library research and conducted limited phone interviews to obtain information from people working in the field. This project describes how foreign agencies are working with local governments and non-governmental organizations to lower HIV/AIDS prevalence in *Tanah Papua*.

Over the years, scholars, academics, economists and heads of various institutions have debated the effectiveness of foreign assistance by analyzing data on economic growth, poverty reduction, and looking at different health indicators. I focus on the role of foreign assistance agencies and multiple organizations working to manage the epidemic. I triangulate my research by looking at international and domestic funding for HIV/AIDS prevention, the current strategies being implemented, by examining barriers to HIV/AIDS assistance programs and prevention strategies. By reviewing reports and evaluations about the planning and implementation of programs, I examine whether or not these programs integrate local contexts to strengthen their message, and achieve long-term solutions in this region. My study also reviews social, economic and cultural factors that influence implementation of HIV/AIDS assistance programs and services to marginalized communities in *Tanah Papua*.

3.1 Project Development

Initially, I was interested in assessing the effectiveness of U.S. foreign assistance

through USAID working in HIV/AIDS in Indonesia. I hoped to interview officials from USAID in Washington D.C., development officials from program implementation agencies contracted by USAID (such as RTI International who implemented the Kinerja program), and members of non-governmental organizations (not funded by USAID) working in HIV/AIDS programs in Indonesia. As my study focused on marginalized populations and foreign assistance, I thought of an approach that would involve "studying up[10]" and "studying down", in an attempt to conduct balanced research.

I planned to gain access to potential interviewees through my personal connections. I did not anticipate any difficulty in gaining access to the minimum number of participants. As intended, I was connected with the Point of Contact (POC) at USAID through my personal contact. I sent them an introductory email to the project that explained what was expected. Despite multiple efforts, I could not get a firm date and time for interviews or names of potential interviewees. Due to time constraints, I determined that I could get reliable data from existing research without the interviews.

To avoid additional delay, I decided to broaden my research and include other bilateral and multilateral agencies working in this region in my review of literature. Therefore, I conducted further desktop research on the work of prominent agencies and their evaluation reports for this region. I developed an analytic framework as shown below in Figure 8, to understand the complex landscape of the main problem areas and potential barriers to success. Due to length constraints I do not discuss all the components mentioned in the framework.

[10] In the 1960s Laura Nader created the term "studying up". She wanted to encourage anthropologists to include cultures in positions of power as part of their study and not just "study down" those who are victims or less powerful (Erickson *et al*. 2001).

Figure 8: Analytic Framework for HIV/AIDS Intervention in *Tanah Papua*

	FRAMEWORK		
	High Prevalence of HIV/AIDS in Eastern Regions of Indonesia		
	Infrastructure	**Policy/Programs**	**Social and Cultural Norms**
Problem	• Lack of Access • Geographic Isolation • No sustainable services • Low capacity • Prevention efforts miss cultural context	Disconnect in planning and implementation: • Local, Regional, District levels • Socio-economic Discrimination • Bureaucracy • Lack of outreach to mobile pop. • Resettlement programs • Under or No representation of local communities • Sex work driven by industry • Marginalization	• Belief Systems • Language Barriers • Attitudes around HIV/AIDS • Self-Stigma/Stigma • Discrimination • Structural Violence
Being Addressed	• Health Posts • NGOs • Other Facilities – Schools • Faith Bases Organizations-Churches/Mosques	• Intervention Assistance • National Aids Commission • Prevention Campaigns • Technical Assistance	• CSOs • FBOs • NGOs • GOI • USAID • AUSAID • Implementing agencies CHAI, AIPH
Missing	• Technology • Local Staff • Local Involvement • Capacity/Training • Facilities	• Better targeted Risks/Prevention campaigns • Better coordination of resources • Improved messaging • Comprehensive outreach • Structural barriers • No confidentiality	• Local language • Develop confidence • Better inter ethnic communication • Changing misconceptions around faith • Lessen stigma • Alternative employment

I used the framework above to analyze the problems and potential solutions about how the HIV/AIDS epidemic is being addressed and what is missing from the prevention

strategies. I extensively researched the published literature on my area of study. From these documents, I was able to identify the gaps in service delivery to *Tanah Papua* and the barriers to prevention strategies, as I have discussed in my literature review in chapter four.

To learn further about NGOs and implementing partners working on the ground, I emailed known scholars based in Australia, such as Leslie Butt and Jenny Munro, whom I have cited in my paper, as they have conducted extensive research *Tanah Papua*. They both responded promptly and gave me few points of reference for my research. I also emailed my contact at the World Health Organization (WHO), who was able to refer me to the people who work in the HIV/AIDS program at the Jakarta office. The WHO office in Jakarta gave me a list of NGOs operating in the area. Upon receiving the list, I began to send emails to solicit interviews with people who worked for organizations in Papua and West Papua.

3.2 Research Methods and Timeline

The research period for this study was approximately six months from June 2014 to November 2014.

Initially I had scheduled approximately two weeks of time for visiting officials in Washington D.C. to conduct interviews with selected informants. I used qualitative methods to collect and analyze data. I collected information for this research using two research resources: The library research/desk review approach and limited phone interviews allowed me to integrate multiple perspectives of people working in HIV/AIDS.

I used library/desktop research for: i) information about foreign assistance

agencies working in *Tanah Papua*; ii) the debate on foreign Aid; iii) foreign and domestic funding for HIV/AIDS programs to Indonesia; iv) NGOs, CSOs and FBOs working in *Tanah Papua*; v) prevention strategies being implemented in *Tanah Papua*; vi) barriers to prevention efforts.

I used one telephone interview with a person who works for an implementation partner of the Australian government to gain any information that is not covered in my review of literature. I dedicated two months to reading and reviewing the background and literature, one month to organizing and conducting interviews and three months to analyzing my data and drafting my study.

3.2.1 Library/Desktop Research

Since my interviews with the mission director to Indonesia and other development officials were not feasible, I searched key websites including USAID, World Health Organization, Australian government and found evaluation reports and audits of programs by scholars, economists, policy consultants and field workers.

Figure: 9 Search Terms and Sources

Key Terms	**Search engines & Database**	**Journals**	**Websites**
HIV/AIDS AND Indonesia	Google scholar	PubMed	World Health Organization
Indonesia AND health OR aid	EBSCO Publishing	Public culture	United Nations
Foreign assistance AND effectiveness	JSTOR	Economic perspectives	USAID
HIV/AIDS AND prevention programs Indonesia	Online Journals Search Engine	Culture, Health & Sexuality	AusAID
USAID AND Tanah Papua	Project Muse	Asia Pacific Media Educator	UNAIDS
Behavior Change AND Condom use	ProQuest	Lancet	CIA World Factbook
Health Communication AND HIV prevention	Global Health	ScienceDirect	

I searched for key terms using multiple search engines, databases and websites and my key word research returned articles from various journals and peer reviewed literature. My main research questions were:

- What are the current HIV/AIDS prevention programs in *Tanah Papua* and how do they involve local NGOs and local communities?
- Are local attitudes, beliefs and preferences taken into account when designing and implementing the programs?
- Who are the most-at-risk groups and how have programs attempted to reach them?
- What implementation models are having the greatest impact to manage HIV/AIDS?
- What are the main barriers to effective HIV/AIDS prevention?
- What have been some unintended consequences?

3.2.2 Interviews

I interviewed one person who is non-indigenous and an Indonesian of Muslim faith and works as a GIPA (the greater involvement of people living with HIV) officer with one of the implementation partners. This helped me to "study down" and learn about the epidemic from someone in the field. I was able to gauge my informant's level of involvement in HIV/AIDS prevention strategies and also get their opinion on how effective the government is at local levels. I developed a separate set of questions for this interview to gain an insight into how the community is considered in the design and implementation of programs and what are some of the obstacles faced by people. This approach helped answer the following research questions:

- Does the role of community organizations help strengthen implementation of foreign assistance programs?

- Are community workers helpful in HIV/AIDS prevention?
- What is the level of response of the community to engage these programs?
- What are some of the major barriers to these efforts?

The phone interview I conducted lasted a little longer than one hour due to the slight language barrier with my informant. Because of the remoteness of my informant's location, I experienced technical difficulties, such as poor Internet connection, while trying to schedule and conduct the interview. I asked questions along the lines of my areas of study and asked for permission to record the interview. I also took handwritten notes. The participant requested anonymity when answering some of the questions. To protect my informant's identity, I assigned a pseudonym calling him/her Atma.

I also emailed a questionnaire to one other potential participant. She preferred participating via email, stating it would be easier for her, as she had to arrange for an interpreter due to the language barrier. I developed a set of standard questions and some questions were specific to the organization's work. Although the intended participant sent me her signed consent form, I did not receive any information from her.

3.3 Solicitation and Consent Procedure

I presented the consent forms via email to the interested participants, explaining the purpose of my research, their role in the process, and their rights as participants. My point of contact at WHO informed me of the language barrier that I would encounter in my outreach to NGOs, especially if I were to conduct phone interviews. It would require the interviewee to arrange a translator to interpret into the local language. I requested that participants review the documents and, if they chose to participate, type out an electronic signature at the bottom of the form. I informed the participants that an electronic

signature functions like a written signature and shows their consent to what was written on the form. I encouraged the participants to ask questions and seek clarification if needed prior to signing the form.

I received two consent forms back with participant signatures and filed them on my computer. But, as mentioned earlier, I was only able to interview one participant, as I did not hear back from the other participant.

3.4 Potential Risks to Participants & Minimization Strategies

During the interview, if I sensed that the participant was tired, or felt uncomfortable answering some questions or had any other questions, I paused to address this issue. During my telephone interview, I was aware of the language barrier and had to repeat the questions and answers a few times to make sure we both understood the context. I also made sure to ask the participant if they would like to take a short break.

As I was not able to ask all my questions in the first interview, I requested to schedule a second interview. I sensed that the participant was enthusiastic about my topic and agreed. Confidentiality of informant data was ensured because all personal identifiers (name, age, address) were removed from the transcript.

3.5 Potential Benefits

My study adds value to the existing academic literature on HIV/AIDS initiatives and prevention strategies for marginalized populations in Eastern Indonesia. It draws on health initiatives being implemented by foreign assistance organizations and the Government of Indonesia that are intended to reduce HIV/AIDS prevalence in *Tanah Papua*. My participant can potentially benefit from the findings of the study, as it indicates barriers that make such programs ineffective. The study attempts to recognize

the barriers and suggests a localized approach to help improve services for marginalized populations. Each organization can gain a fuller understanding about the constraints facing marginalized communities and how best to serve them. The study adds to valuable literature explaining the socio- cultural challenges in Indonesia that need to be overcome at national, provincial and district levels.

Chapter Four: Literature Review

4.0 Introduction

In this section of my study, I describe how other researchers have explained the rising HIV/AIDS prevalence among indigenous Papuans in *Tanah Papua*. It is noteworthy that other researchers present this problem from a specific standpoint, such as studying only stigma and discrimination or marginalization as reasons for this problem. My study draws on four bodies of literature that are interlinked to assess why HIV/AIDS prevalence is on the rise in *Tanah Papua* (i) foreign assistance, economic growth and health, (ii) social and cultural anthropology, (iii) behavior change theory in communication (iv) the growing role of civil society, non-governmental, and faith based organizations in HIV/AIDS prevention. My work adds to the existing literature by providing an overall assessment of why HIV/AIDS is persistent in *Tanah Papua* and why a "one size fits all," blanket prevention approach is not appropriate in this region. I draw on other scholarly research and synthesize all the important components to HIV/AIDS prevention. In some instances, I apply the experiences of the Dani ethnic group as examples.

I have organized this review of the literature in five main categories: First, in section 4.1, I review literature on foreign assistance. Second in 4.2, I review arguments on foreign assistance for HIV/AIDS. Third in 4.3, I examine HIV/AIDS prevention strategies such as the use of condom promotion in local communities implemented by foreign agencies like PEPFAR, and by local organizations. I examine HIV/AIDS behavior change communication (BCC) strategies that use social marketing approaches

with a focus on modifying sexual behavior. These strategies include: 4.3.1 HIV/AIDS prevention campaigns. Fourth in 4.4, I study specific barriers that are mentioned by other researchers in literature on HIV/AIDS and are known to hinder prevention efforts in *Tanah Papua*. Most barriers, I review are interlinked to socio-economic factors and include: 4.4.1 marginalization; 4.4.2 structural violence; and 4.4.3 stigma and discrimination. Fifth in 4.5, I examine the literature that covers commercial female sex workers to explain why HIV/AIDS prevention and outreach to marginalized groups is not decreasing in prevalence. Finally, in 4.6, I summarize the review.

4.1 Foreign Assistance Debate

Foreign assistance is also known as international or development aid given by bilateral and multilateral donors to poorer recipient countries (Phillips 2013). Bilateral assistance is aid given by the government of one country to another through its development agencies, and multilateral assistance involves funding from multiple institutions such as the International Monetary Fund, United Nations, and the World Bank.

Donors have their own objectives according to which they give multiple forms of aid to recipient countries, such as for development, economic growth, poverty reduction and humanitarian aid (Burall and Roodman n.d., 3). Aid agencies, their departments and implementation partners monitor and evaluate outcomes to varying degrees of rigor and inclusiveness. The evaluations may be biased based on the practices and policies of agencies and the administrating departments (Blue, Clapp-Wincek and Benner 2009). A plethora of literature indicates that foreign assistance is tied to political, diplomatic, and economic interests of donor countries. According to Finn Tarp, Director of United

Nations University-WIDER, "foreign aid is not always a free resource transfer and often arrives with economic and political conditions" (Tarp 2012).

Therefore, the debate on foreign assistance involves polarized opinions from two schools of thought, with a particular focus on aid outcomes. One side of the scholarship argues in favor of aid effectiveness while the other side argues that foreign assistance is ineffective or even harmful. My study does not add any new information to this debate, but the review of this controversy is important to understanding foreign aid and outcomes in relation to HIV/AIDS programs.

The debate about foreign assistance, in the context of poverty alleviation, economic growth, and managing infectious diseases, is not new (Lum 2008). "Aid optimists," such as economists, Jeffrey Sachs, David Dollar and Craig Burnside, continue to argue in favor of foreign aid, calling it a powerful tool for economic growth and development. Their argument depends on good governance, sound policies, and transparency in recipient countries, stating that these elements are essential for allow aid to be effective (Wright and Winters 2010). In a recent article, "The Case for Aid," Jeffrey Sachs refutes critics of foreign assistance. He points out that large-scale foreign aid has achieved remarkable results in improving public health in poor countries, such as expanding health programs and increasing coverage for vaccinations and malaria control (Sachs 2014).

In contrast, "aid pessimists," such as economists William Easterly and Ross Levine, argue against foreign assistance. They state that foreign aid along with political and economic conditionalities levied on countries has done more harm than good (Wright and Winters 2010) (Easterly 2003). Easterly calls the current aid agenda a "heroic

simplification" and claims that aid bureaucracies in donor institutions foster a top-down approach that benefits only a small number of people for a limited time (Easterly 2003). Other aid skeptics, such as Rajan, Subramanian and Younger, argue that foreign assistance can negatively impact a country leading to reluctance by national governments to invest in their own countries (Mishra and Newhouse 2009; Easterly 2006). Easterly argues that aid can create economic dependency in poor countries and worsen health outcomes. Other cynics of aid, such as Sofia Gruskin *et al*., indicate that the effectiveness of aid is dependent on overcoming structural barriers, such as poverty and low economic development (Gruskin *et al*. 2013).

A complex, causal relationship exists between poverty reduction and positive health outcomes. To achieve the latter, it is also important to look at factors such as nutrition, sanitation, and access to health services. Simply removing barriers, such as extreme poverty and low economic development will not automatically improve health outcomes in a linear fashion.

The growing role of non-governmental and civil society organizations in recent decades cannot be neglected. Non-governmental organizations either work independently or assist larger agencies in program implementation at local levels. Such organizations also have advocates, such as professor Kusman Ibrahim, and opponents such as scholar James Pfeiffer. Professor Ibrahim *et al*., indicate that aid in the form of training, capacity building, and technical assistance given to local non-governmental organizations can improve community health systems and benefit local communities. With the necessary tools, communities can achieve long-term self-sustainability (Ibrahim *et al*. 2010). As also argued by economist Joseph Stiglitz, in developing countries, a strong civil society

and citizen participation is essential in the decision making process to achieve sustainable growth and development (Stiglitz 2002). Whereas, with the growth of NGOs, James Pfeiffer *et al*. find that "Proliferation of NGOs has provoked "brain drain" from the public sector. This has led to luring workers away with higher salaries, fragmentation of services, and increased management burden for local authorities in many countries" (Pfeiffer *et al*. 2008).

Measures like the Paris declaration[11] are set up as a system to evaluate how aid is being used in recipient countries. The principles emphasize developing capacity and strengthening civil society with a "bottom up approach" to achieve development goals, along with rigorous monitoring and evaluation to show evidence-based outcomes.

4.2 Assistance for HIV/AIDS in Indonesia

Regarding foreign assistance for HIV/AIDS, academics Caryn Peiffer and Constantine Boussalis find that HIV infection rates vary globally. In Indonesia, there has been a rise in new infections, in the provinces of *Tanah Papua*, the subject of this study (Peiffer and Boussalis 2010, 557).

Addressing the heterogeneity of HIV prevalence, Professor Tim Allen from the London School of Economics suggests that global aid assistance alone cannot manage transnational epidemics like HIV/AIDS. Individual national policies and local public health capacity are important factors to ensure an effective response (Allen 2004, 1123). Agung Laksono, the Coordinating Minister for People's Welfare also states, that, above all, Indonesia needs "good leadership and governance" in order to prevent "1.2 million new HIV infections by the year 2025" (Laksono 2010, 1).

[11] Paris declaration is a set of principles agreed upon by global bilateral and multilateral donors with the aim to enhance foreign aid effectiveness in developing countries.

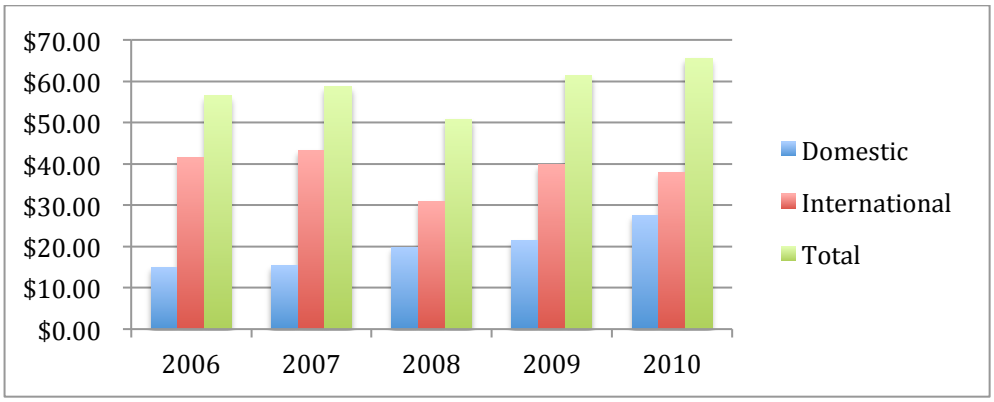
According to Hind *et al*., as Indonesia progresses economically toward a middle-income country, it is expected to eventually lower its dependence on foreign financing for the health sector. A 2011 report by AusAID reveals that Indonesia should be able to fund its own HIV/AIDS response by 2016, reducing the financing it receives from Australia (Hind *et al*. 2011). As foreign funding will decline in the near future, it is necessary for Indonesia to strengthen its national mechanisms, improve coordination among service providing agencies, and improve HIV/AIDS related service delivery at local levels. An effective HIV/AIDS response also requires the country to commit its domestic financial capacity toward funding for HIV/AIDS at provincial levels (Hind *et al*. 2011, 2).

The National HIV and AIDS Strategy and Action Plan 2010 – 2014 projects that Indonesia will need approximately US$1.1 billion (of which 57% will be allocated to prevention) to conduct its National Strategy and Action Plan (Laksono 2010, 9).

Data in Figure 10, below shows that the total amount (domestic and international) invested on HIV initiatives from 2006 to 2010 increased from US$56,576,587 to US$ 69,146,880. Domestic spending increased from US$15,038,057 in 2006 to US$ 27,779,280 in 2010. International funding remained level from US$41,538,530 to US$ 41,367,600, probably reflecting the global recession of 2008 (Public Citizen 2014). The international stakeholders include: The Global Fund, United States Agency for International Development (USAID), the United Kingdom, Australian government through AIPH (Laksono 2012). Despite the overall funding increase, data from Figure 11, below from the Ministry of Health (MoH) shows a sharp rise in new HIV infections from 7,195 in 2006 to 21,591 and AIDS from 2,873 in 2006 to 4,158. The discrepancy between total HIV/AIDS funding and the rise of new infections is central to my thesis about

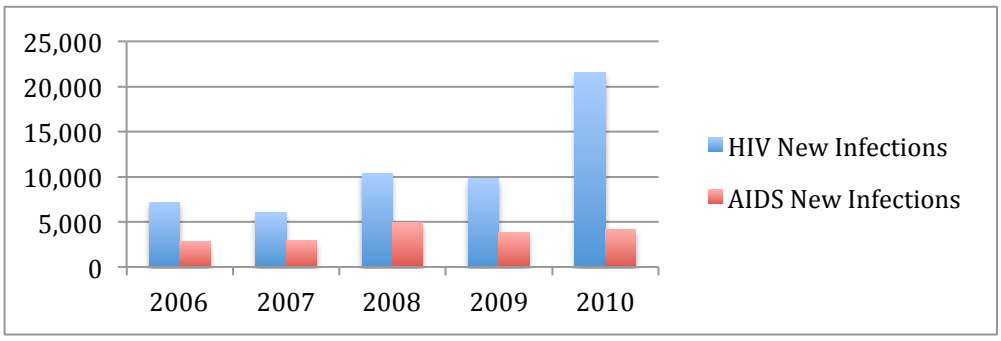
prevention effectiveness as discussed below.

Figure 10: Domestic & International Expenditures on AIDS from 2006-2010 in Millions of US$



Source: NAC, NASA reports 2006-2008. NASA Prelimenary report (unpublished) for 2009-2010 Indonesian National AIDS Commission 2011, 43; Public Citizen 2014

Figure 11: New HIV and AIDS Cases in Indonesia



Source: MoH. Report on Situation of HIV and AIDS. Second quarter (June) 2011.The New HIV Infection rate is provided by MoH (Laksono 2011, 32)

4.3 Behavior Change Communication

Indonesia with the help of multiple organizations is using behavior change communication (BCC) to address the rise in new infections at a countrywide level. Typically, in the context of HIV/AIDS three theories of communication are applicable: Behavior Change Communication (BCC), Social Change Communication (SCC) and Information Education and Communication (IEC). For the scope of this project, I focus

on behavior change communication. My research indicates that behavior change communication is applied predominantly in HIV/AIDS prevention programs in *Tanah Papua*. According to Family Health International, an implementation partner for USAID, now known as FHI 360:

> Behavior change communication (BCC) is an interactive process with communities (as integrated with an overall program) to develop tailored messages and approaches using a variety of communication channels to develop positive behaviors; promote and sustain individual, community and societal behavior change; and maintain appropriate behaviors (Family Health International 2002).

The lack of a cure for HIV/AIDS has reinforced the significance of behavior change as a critical strategy for reducing HIV infections and AIDS related mortality. It involves influencing or modifying peoples' behavior toward safer sex practices, such as by the use of condoms. Behavior change communication has been adopted by many development organizations to mediate HIV/AIDS prevention in poorer countries. Historically, this approach was based on a top-down structure (directed or controlled by the highest levels of management) of communication and information dissemination. Due to the growing ineffectiveness of the top-down model in developing countries, this model was changed to enable the "balanced exchange of information and experience" (Mansell 1982). The new model emphasized a participatory approach in development work, and the role of "effective health communication" gained momentum as a defense against the spread of AIDS. As also stated by Prof. S. Ratzan of Columbia University, "until a vaccine or cure for HIV infection is discovered, communication is all we have" (Ratzan 1993).

In the 1980s, the World Health Organization (WHO) urged developing countries to initiate HIV/AIDS programs (Allen 2004, 1124). According to Professor Allen, the initial HIV/AIDS programs implemented in poor countries focused on behavior change and health education. In the 1980s and 1990s, influencing behavior change through health communication and media became the main tool to promote HIV/AIDS prevention and drive social change in the world (Cullen 2009). But sex behavior change through communication is only a weakly effective strategy due to stigma, fear, and marginalization. It was only in the era of anti-retroviral treatment (1990s onward) that people came forward to be tested and treated (Allen 2004, 1124).

To address this problem, while serving as Director of the HIV/AIDS Department at the World Health Organization, Dr. Jim Yong Kim[12] founded the first global Antiretroviral Therapy program (ART). He noted that "treatment is a point of entry, not an end in itself" and a collaborative effort between international NGOs, multi-lateral agencies and national governments is needed to advocate medications, counseling, effective training for health workers and rapid testing and diagnostic programs (Butt 2011, 322). There are now scholarly arguments that suggest that the advocacy for HIV medications displaces HIV/AIDS prevention as a priority (requoted in Butt 2011, 322: Nguyen 2009). For instance, ART lowers the viral load and assists in lowering HIV transmission. But ART used solely as a form of prevention might avert people from changing their sexual behaviors and work against the behavior change models of prevention. Clearly, the two prevention strategies (ART as prevention and BCC messaging) must work in parallel.

Currently, organizations are applying behavior change communication through

[12] Currently President of the World Bank.

social marketing tools that attempt to enhance development projects and bring positive changes in communities. By engaging the communities, BCC "strives for behavior change not just information dissemination, education, or awareness-raising" (The World Bank IBRD-IDA 2014). This is a participatory approach that aims to deliver enhanced results for social transformation by applying a localized method toward changing people's "attitudes" and "behaviors" (Sparks 2007). This participatory approach is an integrated process that involves the transformation of social structures before changing individual behavior. Sociologist Max Weber, stresses that 'change' in society is a result of 'social action' that is enacted by an individual. Therefore, by first changing a person's traditional way of life and by influencing their 'state of mind' at an individual level, change can be brought at a societal level (Sparks 2007). In the context of HIV/AIDS in *Tanah Papua*, behavior change at an individual level as well as at a community level is necessary.

In *Tanah Papua,* prevention approaches that undermine or question long-standing cultural practices are ineffective because they do not resonate with the people. For example, national level campaigns are designed for a *concentrated* epidemic and applied to a generalized epidemic and have not worked at local levels because they do not recognize Papuan community beliefs, traditions and reify the ethnic differences between indigenous and other communities. Media campaigns and posters focus on drug use and show infected syringes or use photos of non-indigenous people who live in coastal towns and look different from the highlanders. Papuans do not understand the information and feel that the messages does not represent them or apply to them (Simonin, Bushee and Courcaud 2011, 189).

While prevention efforts are being undertaken by organizations and local levels of government, Agathe Simonin, Jennifer Bushee and Amélie Courcaud observe that the majority of HIV/AIDS campaigns at a national level have been ineffective at local provincial and district levels because they do not emphasize HIV transmission through unprotected sex. For instance, the general ad campaigns directed toward injecting drug users, a problem in Indonesian cities but not in *Tanah Papua*. "In fact, less than 1% of HIV transmission in Papua occurs through drug use and sharing of needles" (requoted in Simonin, Bushee and Courcaud 2011, 189: Indonesian Central Statiscs Agency 2007). As mentioned earlier, among Papuans a moral component works better in gaining their interest in the subject and therefore, a blanket campaigning approach is not useful in this area (Simonin, Bushee and Courcaud 2011, 190). HIV prevention strategies in Indonesia use mass media to promote condoms, in the general, as well as in high-risk populations, such as with female commercial sex workers (Fishbein 2000, 273). However, Dr. Pandu Riono from Family Health International, and scholar Saiful Jazant found that when the government initiated condom campaigns, it received criticism by religious groups in Indonesia who implied that such campaigns could encourage promiscuity (Riono and Jazant 2004, 86). According to Allen, condom use also remains a controversial strategy to HIV/AIDS prevention because of its association with contraception and religious taboos (Allen 2004, 1124). For this reason, condom promotion can be ineffective when dealing with marginalized communities, such as the indigenous Papuans, who are a faith oriented, traditional community (Allen 2004, 1124).

It is important to find an effective BCC approach that works in *Tanah Papua*. As local organizations have better access and credibility in communities, their involvement

can enhance the ability of prevention messaging to reach more most-at-risk groups. For instance it can improve outreach to female sex workers who operate independently are often not covered in the scope of prevention efforts that are targeted at commercial sex centers. As also suggested by scholars A.E.R Bos, Herman P. Schaalma and John B. Pryor, "health promoters acknowledge that health is a function of individuals and their environments, including families, social networks, organizations and public policy frameworks" (requoted in Bos A.E.R, Schaalma P. and Pryor 2008, 451: Bartholomew *et al*. 2006).

Considering the low-level generalized HIV epidemic in *Tanah Papua,* a report by Hind *et al*. suggests that 'combination prevention' programs that include biomedical, structural and behavioral aspects are necessary. They argue that scaling up this approach is essential to stopping the ongoing epidemic in these provinces (Laksono 2010, 44) (Hind *et al*. 2011, xv).

4.3.1 HIV/AIDS Prevention Campaigns

Organizations, such as USAID, are assisting in HIV/AIDS prevention by providing technical assistance to CSOs, such as *Yukemdi*, based in the Wamena, to expand their prevention outreach to marginalized high-risk populations. The campaigns many times fail to reach Papuans living in the highlands. Interviews conducted by Butt *et al*. showed that amongst 196 respondents from across the province, only 159 (81%) respondents had heard of AIDS and only 57 (29%) could identify a condom. Among Papuans from rural areas, only eight percent knew of condoms, not ever having used one themselves (Butt, Numbery and Morin 2002, 287).

Florence Quénet finds that the national HIV/AIDS prevention campaigns do not

acknowledge Papuan culture and their health seeking behaviors. The Papuans' respect for their natural environment and their traditional beliefs have an effect on their health. For instance, the men resist the use of condoms because they fear that if sperm touches the soil it would make them sick, and that disposing the condoms would cause it to touch the soil (Priolet and Quénet 2010). In addition, Andrew Marshall and Bruce Beehler note that Papuans have considerable knowledge of traditional medicine[13] (Marshall and Beehler 2007, 116).

Leslie Butt finds that most health campaigns geared toward HIV/AIDS prevention and Papuans are part of a national mandate imposed by non-Papuans and do not integrate cultural values in the interventions (Butt 2005, 420). This suggests that global and national agendas are not guaranteed to work at localized levels and foreign agencies often run against Papuan ideologies. Leslie Butt also states that, "global ideals about preventing HIV/AIDS are difficult to put into practice at the local level" (Butt 2012, 35). Stigma, discrimination, and religious taboos about discussing sexual behaviors are also reasons that put people at high risk of infection in *Tanah Papua.* These issues are not included or addressed in the prevention campaigns. As argued by Symonds and Kammerer *et al*. "education and prevention programs on HIV might be more effective if they were to take into consideration the cultural context and sexual behaviors of marginalized ethnic minorities" (requoted in Jerez 2014, 37: Symonds 2004, 353; Kammerer *et al*. 1995, 53).

Similarly, the importance of cultural taboos was evident when organizations such as the United Nations Children's Fund (UNICEF) implemented HIV/AIDS prevention programs in schools to reduce the numbers of infections among youth. These programs have not been successful in rural areas because research uncovered that about 38% of

[13] Traditional medicine is beyond the scope of this paper.

children between the ages of seven and 15 did not attend school in the Papua highlands. A report by the IRIN indicates that in 2010, the Provincial government in Papua partnered with UNICEF to add HIV education as part of the school curriculum. Research shows that the integration included developing curriculum to add HIV/AIDS education, training teachers to discuss the issue and creating support for HIV policy at the district level. Although the program was effective in reaching approximately 876 teachers across 58 secondary and 47 primary schools (Integrated Regional Information Network 2013), aid workers sensed reluctance from teachers to talk about HIV transmission through sex with their students due to the cultural and traditional taboos on discussing sexual intercourse.

My research indicates that to achieve behavior change among this group, media and communication campaigns need to tailor education and prevention that address the unique social and cultural conditions in the province. Cultural insensitivity can make it difficult to achieve effective behavior change (Bobii 2013). In addition, prevention programs have to create a favorable environment for social change keeping in mind that behavioral change is a process that takes time, and occurs within communities not through imposition, but through continuous education that creates awareness and motivates transformation[14].

4.4 Barriers to HIV/AIDS Prevention

So far, the literature review shows that global BCC strategies need to be adjusted to the local context, especially when dealing with marginalized communities with entrenched cultural taboos. Now, I highlight some of the barriers researchers have identified as being inherent in the system that affect HIV/AIDS prevention. My literature

[14] banicheema.wordpress.com.

review focuses on marginalization, structural violence, stigma and discrimination as the most frequently mentioned barriers to HIV/AIDS prevention[15]. Structural violence and social inequality in the indigenous population contributes to marginalization, stigma and discrimination.

4.4.1 Marginalization

Prominent scholars, such as Leslie Butt and Jenny Munro, who have extensively researched the spread of HIV/AIDS in *Tanah Papua,* indicate that the provinces' political, socio-economic, transmigration policy and cultural environment all contribute to the marginalization of the indigenous population.

According to Susan Rees *et al*., Indonesia granted the Papua province "Special Autonomy" in 2001, calling for the establishment of a Papuan people's council (Rees *et al*. 2008, 641). The setting up of the council was intended to empower the indigenous people of Papua by protecting their basic human rights and raising their standard of living. However, Quénet finds that, due to the dominance of Indonesian in-migrants in *Tanah Papua*, the Papuan people's council has not attained its goals and 55 % of Papuans continue to live below the poverty line (Priolet and Quénet 2010).

Dr. Jim Elmslie, co-convener of the West Papua project at the Centre for Peace and Conflict Studies, the University of Sydney, suggests that the *transmigration* (the movement of people from one place to another) to this province has led to communal conflict between the indigenous Papuans and in-migrant Indonesians. Violence and separatist ideologies[16] have aggravated racial and religious tensions between Melanesian Christian Papuans and Asian Muslim Indonesians, leading to the exclusion of the

[15] [15], [16],[19],[23],[81].
[16] Communal violence in Papua province is relevant information to understand the socio-cultural context but is beyond the scope of this paper.

indigenous from socio-economic opportunities and diminishing their access to health services (D. J. Elmslie 2010). Jenny Munro and Stuart Kirsch (2004) argue, "Papuans are marginalized, colonized, and subjected to state-sponsored killings, torture, racism, and exclusion[17]"(requoted in Munro 2004: Rutherford 2001, Ballard 2002, Kirsch 2002, Budiardjo 1988, Osborne 1985).

Jenny Munro states that the indigenous Papuans are economically dominated by Indonesian in-migrants and are underrepresented in the government, hindering their chances to prosper as a community (Munro 2013, 27; Priolet and Quénet 2010). According to IRIN, about 80% of Papua's indigenous people live in rural areas. Although *Tanah Papua* is under Indonesian sovereign rule, of the 33 provinces, it has the lowest levels of human development (Integrated Regional Information Network 2014; 2013). The transmigration into the highlands led to socio-economic empowerment of in-migrants over Papuans by creating competition for natural resources and land. The Indigenous Papuans largely practice subsistence agriculture (Schwimmer 1997). Marshall and Beehler state that although the local economy of this province relies on agriculture, the timber, gold and copper mining industry and commercial fisheries, oftentimes, income provided by these sources of employment are not adequate (Marshall and Beehler 2007, 1161).

In *Tanah Papua* poverty causes groups of men to leave their villages and travel to mining areas or towns to find alternative means of livelihood. Their mobility isolates them from HIV/AIDS prevention outreach due to their remoteness. Men who move away from home often do not get tested or become aware of contracting the disease. It is

[17] Political conflict in Papua is important to understanding structural violence. However, it is not is the scope of this paper.

difficult to determine the impact of this epidemic in the Papuan highlands because most people do not get tested some evidence suggests that the prevalence rate maybe as high as at 5% or 10% (requoted in Simonin, Bushee and Courcaud 2011, 187: Butt 2005; Rees *et al*. 2008: Butt *et al*. 2010).

In *Tanah Papua*, the Papuan population demographic has been declining over the years due to number of reasons.[18] In 1971, the indigenous peoples were a majority in the province comprising 96% of the population (Rees *et al*. 2008). As Figure 12 below shows there is a drastic difference in the annual growth rate[19] between the two population groups.

Figure 12: Shows the Annual Growth Rate for Papuans and Non-Papuans (in-migrants) (D. J. Elmslie 2010)

Population	Year 1971	Year 2000	Annual Growth rate
Papuans	887,000	1,505,405	2%
Non-Papuans (in-migrants)	36,000	708,425	11%

Dr. Elmslie, projects that by 2020, West Papua will comprise of approximately 30% Papuans and the non-Papuans will become a majority comprising 71% of the population in this region (D. J. Elmslie 2010). Dr. Elmslie states, "the Papuan growth rates are unlikely to increase, and may well decrease as the Papuan population receives poor health services and battles an HIV-AIDS epidemic" (D. J. Elmslie 2010). The large-scale migration into the province due to the natural resources industry has also displaced many Papuans of their land. All these factors have converted the Papuans into a minority

[18] Military operations against Papuans, diseases, government family planning programs, loss of land and natural resources – this is important contextual information beyond the scope of this paper.
[19] Growth rate refers to an increase in the number of individuals in a population at a given period of time.

group in their own region, resulting in their marginalization.

Leslie Butt *et al*. researched further differences among the two groups. The in-migrants blame cultural elements (such as Papuan tradition, unsophisticated lifestyles, and their refusal to acclimate to new Indonesian concepts) to be the cause of their marginalization and adding to their inability to practice HIV/AIDS prevention. The in-migrants blame practices such as polygyny and wife swapping for creating obstacles to modifying sexual behavior among Papuans (Butt, Numbery and Morin 2002, 284). Butt, Numbery and Morin critique such assumptions stating, "Cultural practices are too quickly labeled as promiscuous and problematic and are not as a result understood or analyzed in context" (Butt, Numbery and Morin 2002, 284).

Anthropologist Eben Kirksey implies that the Indonesian in-migrants' control of the provincial government plays an active role in suppressing Papuan culture. Papuans are deliberately excluded from health services and the formal economy, contributing to their impoverishment. Kirksey argues that the provincial governments discriminate against indigenous cultures, calling them under-developed and primitive and being unwilling to adapt to Indonesian culture (Kirksey 2002). Marginalization has led to an unequal distribution of power, exploitation of indigenous resources, and deliberate exclusion from socio-economic benefits and inequities in health services. Papuans fear this as another form of colonial rule that fosters structural violence towards Papuans. Elizabeth Brundige *et al*., state:

> The Indonesian government, by its actions, appears to identify the West Papuans as a common ethnic group. In the 1970s and 1980s, the government sought to "Indonesianize" West Papuan education and culture, compelling West Papuans to abandon their "primitive" customs and to speak and dress like Indonesians (Brundige *et al*. 2004).

Marginalization often leads to socio-economic inequalities and lack of resources, which in *Tanah Papua*, is a result of structural violence against the Papuans.

4.4.2 Structural Violence

Sociologist Johan Galtung describes such inequalities through the term "structural violence" (requoted in Parker 2012: Galtung 1969). John Galtung introduced the term structural violence to refer to a form of violence perpetrated by social and institutional structures. Such structures constrain human agency, making basic human needs unattainable (Ho 2007, 3). In this paper, I investigate structural violence through socio-economic and cultural[20] inequities that exist between in-migrant Indonesians and marginalized indigenous Papuans. Johan Galtung discusses "structural violence" as:

> An avoidable impairment of fundamental human needs or, to put it in more general terms, the impairment of human life, which lowers the actual degree to which someone is able to meet their needs below that which would otherwise be possible (requoted in Parker 2012, 167: Galtung 1993).
>
> The violence is built into the structure and shows up as unequal power and consequently as unequal life chances (requoted in Parker 2012,167: Galtung 1969).

Jenny Munro explains the experience of inequity in education in *Tanah Papua* with the concept of 'Diminishment,' using the Dani ethnic group as a case study. Illiteracy in the Papua province is at a high 34.83% in the age group of 15 to 44 years vis-à-vis the national average of 2.30% (J. Elmslie 2013). Indonesians and Papuans' see education as an equalizing tool that leads to upward social mobility and authority.

According to Munro, "Diminishment is a practice of Indonesian rule that shapes Dani experiences of literacy and educational achievement" (Munro 2013, 28). The

[20] Culture includes ethnic, religious and racial disparities. While, economic inequalities can occur due to lack of education.

Indonesian government is an active participant in creating the inequity in education that decreases the chances for Dani Papuans to prosper. The Indonesian bureaucracy systematically lowers educational opportunities for indigenous people by delivering low quality schooling and poor access to schools from rural areas. This further contributes to their marginalization while empowering in-migrant Indonesians with better education. "In Papua, promises about the power of education to create modernity, development, equality, and inclusion take shape in relation to potent forms of diminishment that identify inadequacies allegedly possessed by the indigenous inhabitants" (Munro 2013, 29). In deeper regions of Papua, such as Jayawijaya, the illiteracy levels are about 60% (Munro 2013, 36). Munro argues that Indonesians often patronize Papuans, adding to their experience of diminishment. For example, Indonesian scholar Roosmalawati Rusman, states that Papuan students have "limited cognitive learning capacity and creativity" (requoted in Munro 2013, 30: Rusman 1998).

In addition, Richard Parker argues that structures place people in situations that increase their vulnerability (Parker 2012, 167). Medical anthropologist and physician Paul Farmer has further developed the theory of structural violence in relation to health and illness, suggesting that structural violence is "not the result of accident or a force majeure; it is the direct or indirect consequence of human agency" (requoted in Parker 2012, 167: Farmer 2005). Parker elaborates Farmer's view:

> …unequal distribution of power in society is the root cause of structural violence, and that it creates disproportionate life chances because of disease or poverty. This unequal distribution of power systematically disadvantages – and therefore discriminates against those who hold little or no power in society (Parker 2012, 167).

Thomas Pogge provides evidence that "global institutions," such as the World

Bank and International Monetary Fund, have played a role in creating wider disparities between what he calls the "oppression and power" through "regulations imposed by the wealthy societies and cherished authoritarian rulers and corrupt elites in the poorer countries, contribute substantially to the persistence of severe poverty" (Pogge 2002, 115). In Farmer's view, institutions have contributed to structural violence against the poor and marginalized. This is supported by Allen's argument that HIV/AIDS polices have been mostly effective where they have been implemented among the elite or people living in wealthy countries (Allen 2004, 1123). Sandy Restrepo Jerez uses Burma as an example of 'institutional violence,' where the Junta (the state's law and order restoration council) forced a majority of medical professionals to leave Burma, leading to scarcity of HIV/AIDS health professionals (requoted in Jerez 2014, 33: Beyer 1998, 89-90).

Research shows that structural violence is one of the reasons for the poor delivery of health services for indigenous groups in *Tanah Papua*, at provincial and district levels. Carole Reckinger and Antoine Lemaire's research indicates that the government has not succeeded in setting up health care services and infrastructure in rural areas. Their research also points toward the absence of trust on behalf of indigenous Papuans who consider the health staff to be inefficient and lacking interest in the well being of indigenous people (Reckinger and Lemaire 2013). A case study done in the northern highlands in Thailand tells a similar story, where poverty and isolation have resulted in the Hmong people rejecting the condom promotion campaigns. They view the campaigns as a strategy to shrink the Hmong population (requoted in Jerez 2014, 33: Symonds 2004, 355; Kammerer *et al*. 1995, 68).

The literature above indicates that marginalization and structural violence creates

obstacles for indigenous Papuans to access health care services. In addition to the lack of access, the built in stigma and discrimination associated with HIV/AIDS further handicaps people to seek help or prevention information.

4.4.3 Stigma and Discrimination

HIV/AIDS related stigma and discrimination is largely based on negative perceptions associated with the disease. Stigma often leads to discrimination, causing a series of negative emotions, such as shame and blame, in people. It prevents people infected with HIV from seeking or accepting help due to the fear of social rejection (Earnshaw *et al*. 2012). Stigma can be perceived or internalized, which leads to fear, low-self esteem and isolation.

Additionally, people do not respond well to someone with HIV/AIDS because of its association with death and most often, people react negatively because HIV infections are interlinked to behaviors that do not fit into socio-cultural norms. For example, communities often blame sex workers for the onset of the disease because of their profession (Bos, Schaalma P. and Pryor 2008, 452).

Dr. Mark Dybul and Hon. Michael Kirby state that HIV/AIDS remains prevalent in vulnerable groups who experience marginalization and discrimination in society. For instance, they find that in female sex workers, *MSM* and IDUs rates of infection can reach 30% to 50%, as these groups face inequality in access to services because of stigma and discrimination (Dybul and Michael 2014). As defined by Bos *et al*. “Stigmatization is a complex process that contains cognitive, emotional and behavioral aspects” (Bos, Schaalma P. and Pryor 2008, 452).

Furthermore, Richard Parker and Peter Aggleton argue that stigma in relation to

HIV/AIDS needs to be examined in the context of culture, power and control. Parker states "stigma plays a key role in producing and reproducing relations of power and control" where communities, individuals and the state use it as a tool to create structures of social inequality (Parker 2012, 166). Additionally, Bruce G. Link and Jo Phelan argue that discrimination in public health is not only due to stigma, but is a result of socio-economic inequality in societal structures, describing this as the "fundamental causes" of disease (requoted in Parker 2012, 167: Link and Phelan 1995, 80).

For example, Peiffer and Boussalis suggest "ethnic fractionalization," or a set of people belonging to different ethnic groups, has an influence on health systems and policies towards HIV/AIDS prevention and response (Peiffer and Boussalis 2010, 559). In comparison, Gauri and Liberman argue in their case study of Brazil and South Africa that the fear of stigma in an ethnically divided society can cause the elite to not acknowledge the existence of an epidemic or brush it off as something that is overstated. This action, taken to preserve the elite's reputation, hinders the necessary policymaking to manage the problem (Gauri and Lieberman 2006).

Similarly, in *Tanah Papua*, although social boundaries exist between the indigenous and Indonesian in-migrants, there is a group of indigenous Papuans who are tribal leaders and have managed to attain positions of power. This group of Papuans must navigate tensions between national and local ideologies. On one side, as part of the Indonesian bureaucracy, the Papuan elite has to impart the HIV/AIDS message within the conservative norms of the Indonesian state and make decisions about health policy (Butt, Silence Speaks Volumes 2008, 119). While, on the other hand, they are expected to be the voice of the indigenous people and address their concerns. Yet to maintain their status

and be included among the elite, the Papuans in leadership positions often fail to exercise their power and thus widen the gap in HIV/AIDS prevention efforts.

Other than bureaucratic problems, evidence by IRIN confirms that most health facilities in Papua are located in urban areas of the highlands, depriving 80% of Papuans living with HIV/AIDS in rural areas access to testing (Integrated Regional Information Network 2014). Quénet finds that in the villages that are equipped with necessary instruments for care, Papuans face discrimination by the largely in-migrant staff. In some instances in which indigenous people visit a facility, they feel uncomfortable and do not feel welcomed by the staff (Priolet and Quénet 2010). As I discuss later in chapter five, Leslie Butt's research reveals that health workers from the Volunteer Counseling and Testing Centers have made discriminatory statements such as the following "HIV-positive persons are dirty, should be shunned and should receive a punishment" (Butt 2012, 187). Research shows that the medical staff at health clinics does not understand Papuan culture or speak the local language, and often come across as discriminatory and morally judgmental. This kind of behavior dissuades indigenous Papuans from seeking help or information at health centers. Below is the experience of 26 years old Yomi, a Dani group member from *Puncak Jaya* district documented by Florence Quénet in 2010:

> If you live in the villages, you have to walk for days to reach the health center in the district's capital, because there's no health staff in the villages. There are community health workers, but if you need more medical assistance you need to go to the district capital. That's why people are dying in the villages especially when they get sick and are too weak to move. When people do reach the health center, they have a hard time talking with the staff because the staffs do not speak the local language (Priolet and Quénet 2010).

Leslie Butt's research also shows that there is still reluctance on the part of health

workers and doctors, who are primarily Indonesian, to share information, distribute or demonstrate the use of condoms (Butt, Silence Speaks Volumes 2008, 124). Butt also finds that there is a problem with condom promotion because, although the campaigns are based on the ABC approach, the AIDS prevention messages at local levels often leave out condom use. She suggests that, to the public, this comes across as if the state is more interested in promoting self-regulation in sexuality than organizing effective HIV/AIDS prevention (Butt, Silence Speaks Volumes 2008, 124).

Upon interviewing four tribal groups, Leslie Butt found that social withdrawal is common among people who tested HIV positive. For the Dani group, "fleeing is an act of agency and an assertion of personal dignity" that allows them to escape discrimination (Butt 2012, 185). HIV/AIDS related stigma and discrimination are prevalent in *Tanah Papua*. Due to traditional and religious structures that do not condone sexual behaviors outside of marriage, oftentimes people who are infected do not seek help. People who are sexually active before marriage do not expose their relationship status or carry condoms because they fear being called immoral and practicing deviant behavior.

Sarah Hewat argues, that ideology plays a powerful role in the lives of young Papuan women, compelling them to hide their courtships because of fear of stigma, thereby increasing their risk of infection. For instance, in Manokwari, a coastal town in Papua, romantic courtships are considered immoral because of their associations with pre-marital sex. (Hewat 2008, 152). Hewat states that traditions such as "bride-price," when a man pays to own rights to a woman's reproductive system, considering it a resource, reinforces that the woman has upheld morality by not engaging in sexual relations outside of her marriage. Therefore, if a woman is found to be HIV positive it

can be detrimental for her because engaging in any other relationship outside the "bride-price" is considered to be "a kind of theft" (Hewat 2008, 158).

Hewat also finds that condom use can be low in this region because carrying a condom can imply "prior planning of a sexual act, which in turn implies awareness and acceptance of oneself as a sexually active subject (Hewat 2008, 164). Therefore, it makes sense that 93% percent of HIV/AIDS cases in this province are transmitted through unprotected sexual intercourse (Somba 2012) and that Papua has the highest number of mortality cases in Indonesia (requoted in Hewat 2008, 151: Departemen Kesehatan 2005).

Matthew Clarke, Simone Charnley and Juliette Lumbers find that educating religious leaders can transform notions associating HIV/AIDS to "sinful" activity and reduce stigmatization of people living with HIV/AIDS by accepting the problem and realizing the need for intervention (Clarke, Charnley and Lumbers 2011, 6). For instance, the participation of *YKB*, a local Christian organization in Papua, has influenced behavior change among Papuans by helping people to overcome fears of stigma around sexual transmission of the disease, which people perceive as immoral behavior due to religious beliefs. *YKB* has programs in 15 sub-districts (Clarke, Charnley and Lumbers 2011, 6). "It involves 99 church congregations from 11 different denominations" (Lumbers n.d.).

YKB works with local communities through their church groups to share information on HIV/AIDS and extends its help to people already infected. It conducts prevention activities by maintaining the Church's values of abstinence while also working with other organizations to promote safe sex practices. In 1999, the *YKB* started "The Sexual Health Program", which has been very successful in training religious

leaders in church and Sunday schools (Clarke, Charnley and Lumbers 2011, 11).

As shown above, there are examples of successful efforts made to change attitudes towards HIV/AIDS. However, stigma and discrimination continue to impede the HIV response in *Tanah Papua*. To understand how HIV/AIDS strategies have targeted high-risk groups, such as FSWs in *Tanah Papua*, the literature below reviews their situation.

4.5 Female Commercial Sex Workers

In *Tanah Papua*, commercial sex work is largely attributed to poverty and economic deprivation (Integrated Regional Information Network 2008). The mining industry has boosted the cash economy in this region and impacted the sex industry because of the influx of new in-migrants. In the *Tanah Papua* region, poverty has forced many Papuan women into prostitution to support their families. In some instances, people exchange sex for food (Groves 2010). According to Leslie Butt, indigenous women do not have feasible opportunities to find alternative sources of employment, such as running a successful business because of the dominance of in-migrants in the local markets (Butt 2012, 42). This is a form of structural violence. As documented by Epidemiologist Elizabeth Pisani and shared in her TED talk, "Sex, drugs and HIV-let's get rational" (2010), alternatives such as factory work are grossly underpaid. Butt indicates that other programs started by the government to create alternative work (such as seamstress work or market vending), have also been "designed to fail" (Pisani 2010) (Butt 2012, 42).

According to Butt, health promotion for FSWs and clients is usually based on a global model of prevention. This model assumes that people will respond positively to

the information (example health warning, safer sex) shared and change their behavior as a result. Butt argues against prevention strategies that are based on the notion of what she calls "rational sex", which assumes human beings apply reasoned thinking to change their sexual behavior in order to reduce risk of disease transmission (Butt 2012, 35). According to Butt, this approach is ineffective in HIV/AIDS prevention at the community level (Butt 2012, 35). Pisani uses rationality to explain the decision of public health policymakers to push for prevention methods, such as condom use, because it is less costly for them to promote prevention strategies than provide treatment to people after they get infected. She says that using condoms is rational and would also make sense for sex workers because catching infections hurts their business. However, Pisani argues that it is difficult to get people to always use condoms, especially in personal relationships outside the sex industry. Therefore, prevention focused on "rational sex" does not work at local community levels (Pisani 2010). Elizabeth Pisani states that public health policies need to be aligned with incentives to make HIV/AIDS prevention effective. In Indonesia the HIV/AIDS prevention policy is merged with its HIV/AIDS prevention strategy (Spratt *et al*. 2007, 9).

The provincial government, in partnership with United Nations Programme on HIV/AIDS (UNAIDS), AusAID, USAID and UNICEF, has promoted condom usage among sex workers and client brokers in urban brothels. Efforts also include free condom distribution to sex workers who make less money (Laksono 2011, 56). The concentration of the program on urban centers, which mostly cater to Indonesians, has been more effective; about 70% of clients of sex workers use condoms. But, the program omits Papuan women who work in the streets, resulting in less than five percent of street sex

workers who used condoms (Butt, Numbery and Morin 2002, 287).

In *Tanah Papua*, the military is also involved in facilitating health check ups for sex workers. Leslie Butt finds that the military supervises the sex industry and also makes profit from this work by providing Indonesian sex workers to brothels (Butt 2012, 38). Scholar Vinh Kim Nguyen uses Agamben's "state of exception" to examine the military's additional control over health service delivery to prevent HIV/AIDS (Mykhalovskiy and Rosengarten 2009). For example, the military forces sex workers to get physical examinations that results in the sex workers' loss of agency, implying that the force is necessary to pevent HIV infections. Butt refers to this as biopolitical intervention[21] (Butt 2011, 323). The Office of Defence Cooperation (ODC), an implemetation partner for PEPFAR/Indonesia, provides prevention training to the Indonesian Military (PEPFAR 2013). Butt argues that the participation of the military creates fears among Papuans about health care, as the military is associated with violence.

Commercial sex work in *Tanah Papua* also illustrates ethnic inequalities[22] in health promotion. This is prominent in the sex industry, which is stratified based on the ethnicity of the sex workers (Butt, Numbery and Morin 2002, 285). Leslie Butt, Gerdha Numbery and Jake Morin's (2002) field research provides evidence of a correlation between the amount of money charged by the sex worker and their ethnicity:

> Indonesian women sex workers are most likely to charge large amounts of money. This is not because Indonesian women are inherently more desirable, but because ongoing colonial relationships place Indonesian women at the apex of ideas of beauty and desire. Elite Indonesian sex workers also benefit from a regional economy, which pours vast amounts of money into the pockets of military and business clients, who are also almost all Indonesians, and who prefer

[21] Bio political intervention is used in context to the right to intervene to save lives from HIV/AIDS.
[22] Employment and socio-economic benefits are not in the scope of this paper.

> Indonesian sex workers (Butt, Numbery and Morin 2002, 285).

Other examples from research indicate that to prevent HIV/AIDS among sex workers, some countries have adopted community mobilization programs, such as the "Sonagachi Project[23]" in India. Also government initiatives, such as the "100% condom program" introduced in Thailand, are known for their success in reducing HIV rates in the country (some research indicates that such initiatives are ineffective in reaching ethnic tribes (Kang *et al*. 2013; Jerez 2014, 33). Dominik Mattes argues, in the case of sex workers, often times it is the clinicians or counselors whose negative inferences influence health seeking behavior and work against prevention efforts (Butt 2012, 35). According to Gruskin *et al*. poor policies can also create barriers for "most at risk" groups to access services. For example, Gurkin *et al*. state "The government in Indonesia notes that the local government bylaws closing prostitution complexes resulted in the spread of street prostituition and make it difficult for local health departmenets to provide services for sexually transmitted disease control/condom promotion" (Gruskin *et al*. 2013, 4). Similarly, a study done in sub-Saharan Africa found that although female commercial sex workers carry a high HIV/AIDS disease burden, they continue to have limited access to prevention intervention (Chersich *et al*. 2013). Although Indonesia is predominantly Muslim, the presence of different religions creates heterogeneity of practices that need to be addressed by prevention campaigns directed toward sexual activity.

4.6 Summary and Implications

Although a combination of initiatives, such as promotion of condoms, alternative

[23] Sonagachi is the largest red light district of Asia in Kolkata, India. The project is a cooperative for sex workers' that empowers them to insist on use of condoms and fight against abuse.

employment for sex workers and the encouragement of HIV/AIDS testing, have been implemented to prevent HIV/AIDS in *Tanah Papua*, such strategies have not been successful due to constraints (such as marginalization, stigma and discrimination) that are linked to structural violence. Scholars Kiat Ruxrungtham, Tim Brown and Praphan Phanuphak also assert that successful prevention strategies are not effectively replicated in areas where people have limited access to resources (Ruxrungtham, Brown and Phanuphak 2004).

In the United States, "aid optimists" and "aid pessimists" have publicly debated the effectiveness of foreign aid (Wright and Winters 2010). However, the literature on foreign assistance effectiveness is controversial. As my review indicates, aid assessed solely based on economic empowerment is insufficient to determine effectiveness in the health sector especially in HIV/AIDS work. My research implies that *Tanah Papua* requires a tailored approach to managing HIV/AIDS and to developing prevention programs in this region. Such programs must recognize the complex intersection of socio-economic, cultural and political factors (Groves 2010).

This literature examines the most prominent components that impede aid efficacy and factors that create developmental gaps in the prevention strategies. It finds that aid given in the form of training to strengthen capacity building and technical assistance at community levels can improve community health systems. However, this is the case only when good governance exists and international programs are aligned with the government's plan at local levels. By good governance I mean that the governments are transparent, do not mismanage funds, and employ proper monitoring and evaluation at provincial and district levels. Since the Government of Indonesia is using BCC to

improve its services at the local levels, the national government must develop separate campaigns that address the unique needs of indigenous Papuans, as I have shown. The delivery of public health services in Indonesia, especially to marginalized communities such as the indigenous Papuans, remains challenging due to the ethno-religious tensions, poor infrastructure and services, the physical and geographic isolation of the rural communities, as well as stigma and discrimination.

> Turning back the HIV/AIDS epidemic is a task beyond individual efforts, no matter how outstanding or heroic. It requires communities, nations and regions to come together in concerted, coordinated action. *Kofi Annan*

Chapter Five: New Data, Conclusion and Recommendations

5.0 Summary

This chapter comprises three sections: in section 5.1, I provide new data on: 5.1.1, additional barriers to HIV/AIDS prevention such as decentralization; 5.1.2, prevention campaigns; and 5.1.3, highlight major themes such as, stigma and discrimination. In section 5.2, I draw a conclusion based on all my research and in section 5.3, I make recommendations on what can be done in *Tanah Papua* to improve HIV/AIDS prevention strategies for marginalized communities.

In this study, through interviews, a review of academic literature and reports produced by donor agencies, I consider the following key questions:

- Why are HIV/AIDS rates climibing in *Tanah Papua* among the indigenous Papuans, despite multi-agency prevention campaigns?
- What are the current HIV/AIDS prevention programs in *Tanah Papua* and how do they involve local NGOs and local communities?
- Are local attitudes, beliefs and preferences taken into account when designing and implementing the programs?
- Who are the most-at-risk groups and how have programs attempted to reach them?
- What implementation models are having the greatest impact to manage HIV/AIDS?
- What are the main barriers to effective HIV/AIDS prevention?
- What have been some unintended consequences?

I use *Tanah Papua* as a case study to better understand the problems associated with managing HIV/AIDS in the context of marginalized communities. The prevalent

HIV rates and future projections indicate that the current approaches and local initiatives need to be redesigned. According to my findings, marginalization, stigma and discrimination are a result of structural violence against indigenous people and remain the most prominent constraints to HIV/AIDS prevention in *Tanah Papua*. I reiterate the need for a more tailored approach, integrating the cultural, religious and political contexts that influence the HIV/AIDS response in *Tanah Papua*.

While there is sufficient funding and assistance from multiple agencies, the current approach to reducing HIV/AIDS rates in *Tanah Papua* has fallen short in achieving its goals. Why does this gap exist? There is limited literature available on the work done in HIV/AIDS in *Tanah Papua* and the literature available is limited, in that it fails to reveal the many barriers to HIV/AIDS prevention.

5.1 New Data

5.1.1 Decentralization

In addition to my emphasis on the socio-cultural, environmental and political barriers that may determine the success or failure of aid programs, my data reveals that, the local government also affects the outcomes of prevention programs in *Tanah Papua*. The technical assistance programs designed to assist governments at the district and provincial levels, are affected by the decentralization of health services in Indonesia (the responsibility of running health services now falls on the local bureaucracies). My informant Atma[24] states that, decentralization has not improved health services at provincial levels because "Some persons in national and provincial levels do not have the same point of view. Even though decentralization has taken place the provincial

[24] As noted in the methodology in chapter four, this is a pseudonym for my informant who is a GIPA officer (Greater involvement of people living with or affected by HIV/AIDS)

government still depends on the national government for funds." According to Atma, post-decentralization, the provincial level should not still be dependent on the national government.

Yet in West Papua, the provincial level government continues to depend on the national government. For example, Atma says, provincial governments rely on national government for support when conducting HIV testing. Also, when they create an annual work plan with the provincial level government, the officials often contend that there is no money for logistical support, such as to pay nurses and doctors. Atma states, "We have many qualified persons here so we have to create a work plan with our own budget so we can get better services." The provincial government supports 60% of the budget and the other 40% comes from the national government. But Atma argues that it is not enough, stating, "Decentralization should be 100% provincial." I am also told that persons working in the district and provincial AIDS commission are ex-government officials and my informant says that although there is no proof of corruption, the budgets for programs are often inflated. Atma states, "If we talk about program, workshops, the people working at district and provincial levels of government talk about money. For a workshop, a receipt of U.S. $100 million is drafted, but in reality the project is for a U.S. $60 million."

5.1.2 HIV/AIDS Prevention Programs

Carole Reckinger and Antoine Lemaire find:

> Until now there has been no serious action from the government but only lip service. HIV/AIDS has become an emergency and it is too late to sit back and do nothing," declares David*, the head of a local NGO. "If we want to save the Indigenous population, and guarantee the survival of our people, then HIV prevention and treatment needs to become a priority in Tanah Papua. David worries that most AIDS

> awareness raising campaigns are developed in offices in Jakarta, far from the cultural and socio-economic reality of Papua. "It would be more useful to look at Papua New Guinea and programmes there which have proven successful." Instead, the official response to the crisis has been to inject large amounts of money into programs with a minimal amount of monitoring and preliminary research (Reckinger and Lemaire 2014).

In addition, Butt, Numbery and Morin suggest that the health system in Indonesia has been ineffective in imparting "AIDS education" because the ministries, such as the Ministry of Education, have resisted in providing sex education for ideological reasons. This has resulted in inadequate and erratic campaigns concentrated mostly on an urban population leaving out Papuans living in rural highlands (Butt, Numbery and Morin 2002, 287, 288). Also the advertisements are focused on prevention by condoms and are sometimes not very clear on the methods of transmission. Butt, Numbery and Morin find that often campaigns show images that are inaccurate about the modes of transmission and easily misinterpreted by the Dani ethnic group. For example, images of people holding hands to represent sexual relationships not only misrepresent the issue but also, due to the lack of knowledge about HIV/AIDS the Dani people misinterpret how HIV infection occurs (Simonin, Bushee and Courcaud 2011, 189).

These scholars also use an example of the town of Merauke to show the effect of brothel based condom promotions especially on Papuan women. They find that the highest number of HIV/AIDS cases is in the town of Merauke where hotel and bar owners in collaboration with the state have tried to keep their sex workers free from any kind of sexually transmitted diseases. The state has provided free medical checkups for sex workers on a monthly basis. In 2001, 172 women got a free checkup at the clinic.

However, Butt, Numbery and Morin find that:

> …even though there are approximately 400 Papuan women involved in sex work in Merauke, in bars, on the street, and in open-air locations, only one Papuan woman out of several hundred patients had been to the clinic for a free checkup in the past year. Is this because of the "cultural problem" or is this because Papuan women do not know of the service, have not received enough information about the risks of unprotected sex (Butt, Numbery and Morin 2002, 288).

My informant Atma also indicated that a collaborative effort between the district and provincial levels has resulted in HIV testing of approximately 400 people from the local government. Although this effort is commendable, it does not address this problem for Papuan sex workers and people living in isolated areas, for whom testing is infrequent.

While prevention is not the main focus of my informant's organization, in instances where they do produce postcards and posters to share information about HIV prevention, it is done in collaboration with experts from other implementation partners. There is no information available about the involvement of the community or people at the grassroots level in designing the material to make it culturally appropriate for the indigenous population.

Atma points out, "We collaborate with 'organizations' and focus on prevention through local radio, television, churches and mosques, to spread HIV/AIDS information." As I have stated earlier, in Indonesia and *Tanah Papua*, there is a strong religious overtone in the discussion about HIV/AIDS. In *Tanah Papua* about 70% of people living with HIV are Christian, therefore, religious leaders and church groups have become more

active in advocating and implementing prevention stratgeies (Clarke, Charnley and Lumbers 2011 7, 11). Most strategies are based on the ABC (Abstinence, Be Faithful and Condom use) approach, yet Simon, Bushee and Courcaud find that oftentimes the moral element of abstinence and faithfulness are included in prevention talks while the use of condoms as a form of prevention is frequently left out (Simonin, Bushee and Courcaud 2011, 190). This shows that donor agency ideologies about morality and sexuality still take presidence over the prevention campaigns. The different ideological beliefs in an ethnically divided society make it difficult to promote "one size fits all" behavior change programs[25]. Non-governmental organizations, international organizations and faith-based organizations all rely on the BCC approach.

A few successful examples include the work of organizations that have included the local communities to design social marketing, mainstream media advertisements and education through peer groups to promote condom use. One example is the Bethesda Health Foundation (*YKB*) that has achieved intended results in its outreach to remote areas. Its efforts are exemplified by the request of other faith-based groups, including groups from the Muslim faith that have approached *YKB* to become involved in their "sexual- health program" (Clarke, Charnley and Lumbers 2011, 12). Another positive example of *YKB's* work is that in partnership with church groups and other NGOs, *YKB* has also involved street children who are HIV-positive in its prevention programs (Clarke, Charnley and Lumbers 2011, 12).

My research also finds that in 2009, *Médecins du Monde* (*MdM*) an international non-governmental organization, started working with indigenous Papuans from the *Puncak Jaya* district. The *MdM* initiative is focused on improving medical aid and the

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health of people living in the highlands. It works toward developing new prevention strategies while recognizing the socio-economic, political and cultural uniqueness of highlanders. By building trust in the community, the organization has been more effective in helping people overcome cultural barriers related to HIV/AIDS and taboos in discussing sex. Before intervening in the community, the organization developed sensitivity workshops on Papuan culture for the staff to reduce discriminatory behavior and stigma.

Médecins du Monde has used peer education, condom demonstrations, and simple images during educational workshops that the people could relate to and easily understand. The staff found that simplifying the images that represent modes of HIV/AIDS transmission was an effective method to disseminating knowledge on the disease. For instance, showing an image of individuals having sexual intercourse helped the groups stay focused on facts about how the disease is transmitted, opposed to just focusing on condom use and protected sex (Simonin, Bushee and Courcaud 2011, 192). The results of the "knowledge-attitudes-practices" survey conducted for 194 households in *Puncak Jaya* district in 2010 showed that people who lived close to the organization had a higher awareness of HIV/AIDS issues and were comfortable asking for condoms (Simonin, Bushee and Courcaud 2011, 192). Although there is a lack of data on the number of people who utilized the services of *MdM*, Magdalena, a 19 years old member of the students' club shares:

> Now I have gained more knowledge on HIV/AIDS through activities facilitated by *MdM* because they don't ignore my Papua culture but use it to convey a message. My friends and I used to think that you can get AIDS just by shaking hands or touching people who have AIDS. Now I am better-informed, and I can share the information with other people,

> particularly friends at school: such as the fact that you don't get AIDS just by touching, or sitting together, or sharing a meal (Priolet and Quénet 2010).

The examples above show that some organizations, by customizing their approach to the local context, have attained success in HIV/AIDS prevention efforts. However, these small efforts are not enough to stop the spread of HIV/AIDS in *Tanah Papua.* Many programs and campaigns still lack indigenous representation. Mari, an *Médecins du Monde* worker, states, "The Community, including Church leaders, and even some of the health staff, perceived condom promotion and distribution as allowing people to do 'free sex'" (Simonin, Bushee and Courcaud 2011, 189). Mari's comment confirms that there is an existing bias in attitudes of people working in HIV/AIDS that impairs prevention efforts.

5.1.3 Stigma and Discrimination

Barriers, such as stigma and discrimination, remain a problem and have to be addressed as part of the global prevention strategy in HIV/AIDS.

> Limited access to information and a low level of education makes most people in my place unwilling to accept new ideas: lack of knowledge about HIV/AIDS, for example, causes stigma and discrimination to people living with HIV.
> *Aster a Western Dani woman working with MdM*

Atma, who works at the grassroots level, states that stigma and discrimination are major barriers to HIV/AIDS prevention and treatment. Atma gave me an example of a current effort to overcome this barrier. Due to fear of disclosure, HIV positive persons do not seek care and that hinder their chances of survival. A part of Atma's work is to help people disclose their status in the hope that it will break stigma related to HIV positive persons. The efforts include working with a photographer and creating a profile of an

HIV positive person by filming him or her to spread the message that one can seek care and lead a normal life with the disease. Atma also told me that there are no groups or communities that advocate for HIV positive people at district levels. So it is often difficult to locate HIV positive persons and, if found, most likely the person is unwilling to share his or her status with the local community. Atma continues to work in the field and encourages people to be brave, specifically by sharing knowledge about HIV with people.

Atma often tells people:

> being positive does not necessarily mean you will die. You can get married and have children. It is difficult to find people to talk about their status especially in places where there are no support groups and where people lack knowledge but in West Papua there are some persons including women who are ready to open their status. We provide better services, doctors and nurses but we don't prepare train or give knowledge to positive persons. *Atma*

In regards to the Papuan people, my informant reiterates that, "they have a special culture. If I want to marry a Papuan lady I have to pay a monetary amount according to her level of education for example, high school or bachelor's degree, so more degrees means more money will be spent to marry her." In the context of HIV/AIDS, if a person's wife is Papuan and dies of HIV/AIDS, her husband is obligated to pay money to her family, but only if the family becomes aware of the couple's HIV status. Atma states that such practices create difficulty for HIV prevention programs because people who test HIV positive are afraid to share information with their spouses in order to avoid having to give money to the family. Also, the neighbors contribute to the high levels of stigma and discrimination by ostracizing the entire family of an HIV positive person. Stigma and discrimination is prevalent at district levels and people living in bigger cities in West

Papua do not face the same problem largely because the highlands are geographically isolated and much harder to reach due to the lack of roads. West Papua is 70% lowland and 30% highland, while the Papua province is the opposite.

The fear of stigma is also prevalent among Papuans in positions of power. Leslie Butt explains the experience of Mr. Damianus Matuan, a Dani tribal leader, whose son died of AIDS. She found that Mr. Matuan was unable to acknowledge the cause of his son's death in public because it would reflect poorly on his health status and work against his political position. Butt states, "For any Dani leader and his followers to sustain the moral view that leaders, by dint of their position in society, have better health than the rest of the populace" is very important to maintain their image and keep the support of the people (Butt, Silence Speaks Volumes 2008, 121).

The Papuan elite blame the Indonesian sex-workers and the military presence in the region for the spread of the disease. Butt's research also shows that a tribal leader, Jakobus Yufu, in the national paper stated, "that the military controls the sex industry in Papua and deliberately brings in infected sex workers to contaminate the indigenous population" (Butt, Silence Speaks Volumes 2008, 117).

In *Tanah Papua*, the ethnic tensions between the indigenous and in-migrants are present in all levels of society. The real cause of HIV/AIDS transmission is lost in the cultural conflicts exacerbated by structural violence. As also shown through other examples in my paper, both population groups blame one another for the spread of disease.

5.2 Thesis Conclusion

HIV/AIDS is a public health crisis in Indonesia. My research has demonstrated

some of the key reasons why HIV/AIDS rates in *Tanah Papua* are not decreasing, despite all the foreign assistance and local efforts. I present a broad range of arguments, from foreign assistance and its outcomes, to the presence of structural and cultural barriers, to HIV/AIDS prevention in *Tanah Papua*.

In *Tanah Papua,* the current BCC approach has not been able reduce HIV/AIDS prevalence for a number of reasons. First, research indicates that the HIV/AIDS prevention messages are implemented at a national level and use mass media such as T.V., radio and print media (such as posters and images). But the information campaigns do not consider the socio-cultural heterogeneity of indigenous Papuans, as I also discuss in chapter four, who are under-informed about HIV/AIDS and modes of prevention. Second, prevention campaigns that use social marketing are designed to appeal to reasonably well-educated audiences and fall under the mandate of national campaigns. While in *Tanah Papua*, the indigenous people have the lowest levels of literacy and human development. Also, their geographic isolation does not allow them to access main forms of mass media. For example, in the Papua province, female sex workers who work independently on the streets are not the focus of preventive strategies that are mostly targeted at urban sex centers.

In addition to the key constraints mentioned in chapter four, my research also finds that structural and institutional challenges exist in Indonesia at the district and provincial levels, some of which are a result of decentralization and the involvement of multiple agencies and agendas. In chapter two and three, I describe problems with monitoring and evaluation that exist in multi-agency programs. I also describe the fragmentation of services.

The generalized HIV epidemic in Indonesia is now in a *concentrated* stage, requiring high levels of response from all agencies to high-risk groups. Since the prevalence rate of HIV/AIDS is 15 times higher in the province of Papua, an efficient response and cultural sensitization is required to reach all groups of people equally. As described earlier in this paper, socio-economic inequities remain prominent in the province of Papua and prevent indigenous Papuans from prospering and taking advantage of health and education services that they are entitled to as citizens of Indonesia. A pattern of structural violence is noticeable in all sectors of Papuan society, exacerbated by government agencies and by the in-migrant Indonesian majority. The underrepresentation of Papuans and their exclusion from health services illustrates this experience.

While tackling the HIV/AIDS epidemic in the Papua province, all the socio-economic, cultural, and political factors need to be considered and discriminatory practices against the Papuan indigenous people eliminated. Through my research I sensed a bias with the following statement made by my Indonesian informant, "Tribal people have many parties, in the party they drink and have sex." Atma also confirms that officials treat *Tanah Papua* the same as other provinces, while implementing programs. But this attitude is not helpful because these provinces are very different in their culture and geography.

As personified by the Bethesda Health Foundation (*YKB*), the HIV/AIDS awareness programs do succeed if HIV/AIDS information is dispensed consciously and campaigned appropriately without bias and within cultural norms and beliefs of communities. If indigenous people develop a connection to an organization, such as in

the case of *YKB,* the intervention and prevention strategies become increasingly effective in encouraging people to seek help and positively impact communities.

5.3 Recommendations

Although non-governmental organizations, foreign assistance agencies and the Government of Indonesia are trying to fill the lacunae in the health care system by providing adequate HIV/AIDS responses, the national and provincial governments need more inclusive efforts through community-based interventions. These are also referred to as "bottom up" approaches involving local people affected by the epidemic in the design and implementation efforts. For instance, researchers Esther Duflo, Abhijit Banerjee and Rachel Glennerster worked with the World Bank and a local NGO called Pratham, to design three interventions to improve the quality of education in rural India. These economists use "randomized clinical trials" to inform and policy by systematically analyzing what interventions actually work in the field. The interventions were random, involving 280 villages in Eastern Uttar Pradesh, India. These researchers found that of the three interventions, the most successful intervention was the one that involved teaching volunteers from the community "a simple technique" to help children read. As part of the strategy, volunteers were trained and urged to begin reading lessons for students after school. Duflo *et al*. state, that:

> …was the only intervention which actually improved educational outcomes, by empowering individuals to improve teaching in their own communities. This suggests that enabling local action which does not depend upon large-group participation may be a means of directly affecting educational outcomes (Banerjee, Duflo and Glennerster 2005-2006).

Projects that involve the community can help bridge the gaps created by the inequities in the system. All stakeholders need an equal voice in order to fully tackle the

HIV/AIDS epidemic; contrary to the "top down" approach on government policy, there is a need for a more inclusive approach that can cope with the tensions between the Papuans and in-migrants to manage this epidemic [26]. As is stated by Nancy Krieger, "epidemiologic research explicitly focused on discrimination as a determinant of population health is in its infancy" (Farmer 2005, 241). She is correct. Community based projects that are successful are bottom up, have no accountability problems, and are culturally sensitive.

I argue that *Tanah Papua* is a special case in need of a more effective HIV/AIDS prevention program. Cultural practices and individual beliefs of people must be understood in order to achieve behavior change. "Culturally appropriate" and simple messages and evidence-based information allow people to think about HIV/AIDS and then make their own choices about practicing safe sex to avert HIV infection (Simonin, Bushee and Courcaud 2011, 194). "Some of the most effective responses to HIV/AIDS epidemic have been those where affected communities have mobilized themselves to fight stigma, discrimination, and oppression" (Parker and Aggleton 2002, 13).

Health messaging can become a more effective tool to engage this epidemic if utilized in continuity and within socio-cultural context. As stated by Paul Farmer "Social and economic forces shape the AIDS epidemic" (Farmer 2005, 40). Therefore, targeted modes of media communication can be useful in reaching most vulnerable populations including sex workers and their clients, young people, and injecting drug users in urban areas. My literature review shows that in order to effectively reach marginalized communities, such as the indigenous populations in *Tanah Papua,* mass communication and education tools must involve locals in the planning and implementation of behavior

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change messages. They must address the social, economic and cultural context in their programming strategy.

No single mode of communication is sufficient to address HIV/AIDS prevention in Indonesia. There is no blanket approach. Prevention programs must use indigenous media sources to make prevention strategies more effective. It is undeniable that health communication can be a powerful tool in the public health field. But communication must be customized to its specific target groups. Media campaigns should be required to include a component that helps overcome stigma and discrimination attached to HIV/AIDS[27]. Multiple disciplines, social and cultural anthropology, epidemiology, and economics, working together in HIV/AIDS prevention, can find a new way to collaborate in order to have successful outcomes.

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